EPILEPSY in Massachusetts

A REFERENCE HANDBOOK

Prepared By:

Epilepsy Program
Massachusetts Department of Public Health
39 Boylston Street
Boston, Massachusetts 02116

Epilepsy Society of Massachusetts, Inc.
3 Arlington Street
Boston, Massachusetts 02116

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INTRODUCTION

An estimated 60,000-120,000 persons in the Commonwealth of Massachusetts, or 1-2% of the general population,* have some form of recurrent seizure disorder, that is, epilepsy. It begins most often in childhood, but can unexpectedly develop in any person at any age. Epilepsy may be a simple, controllable medical condition or it may manifest itself as part of a complex network of medical and social problems.

People with epilepsy, depending on the nature of the individual condition and situation, may experience needs beyond those for medical services. To help them to obtain service, one must identify specific areas of need and proceed to meet each of them, usually through a combination of resources. Since epilepsy is such a common condition, nearly all agencies and programs serving people are serving people with epilepsy, and it would be impossible and unnecessary to list them all here. Because of the stigma historically associated with the condition, however, there remains--in the professional "provider" community, in the general public, and frequently even among those who have epilepsy--widespread ignorance about the nature of the disorder and about resources available for its medical and social management.

In Massachusetts, a few services address themselves exclusively to the problems of epilepsy. The Epilepsy Program of the Massachusetts Department of Public Health and the Epilepsy Society of Massachusetts and related voluntary agencies are sources of information and referral and some offer programs, counseling, advocacy and other services. State and local resource directories supplement the small epilepsy agencies in directing an individual or a family to find help. We urge readers to communicate unmet needs to the agencies concerned with epilepsy and to appropriate medical and human services providers.

We hope that this handbook--in offering an overview of services, programs, laws, background information and helpful hints--will be useful to all those interested in making sure that our many fellow citizens with one of mankind's oldest and least-understood disorders, are not unfairly handicapped by misinformation, prejudice, or lack of services.

The following services are needed by all people with epilepsy:
--medical information and referral
--medical services (diagnosis, treatment)
--medications

The following services may be needed by some people with epilepsy:
--medical and personal identification
--job placement and follow-up
--vocational counseling, training and rehabilitation
--individual and/or family supportive counseling
--genetic counseling
--legal advice and counsel
--life and health insurance
--transportation
--special nursing
--special education
--short- or long-term residential placement
--psychiatric care
--recreational and social activities
--self-help and discussion groups
--financial aid
--emergency medical assistance
--neurosurgery

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* Basic Statistics on the Epilepsies, compiled by the Epilepsy Foundation of America, 1975, published by F.A. Davis, Philadelphia, through a grant-in-aid from Geigy Pharmaceuticals, a division of Ceiba-Geigy, Ardsley, New York.

This handbook summarizes services of the epilepsy agencies and outlines key state and federal services, laws and policies pertaining to the management of epilepsy. Section II offers additional background, information about resources, and "helpful hints." Please communicate additions and corrections to the Epilepsy Program, Mass. Dept. of Public Health, 39 Boylston Street, Boston, MA 02116 (617-727-5822).

This handbook does not list direct service providers or sources of medical services (other than those provided by or funded through the Dept. of Public Health). A person with epilepsy or suspected epilepsy should immediately seek qualified medical care, preferably by engaging the services of a board*-certified or board*-qualified neurologist (or, in the case of children, a board*-certified or -qualified pediatric neurologist). A few physicians, known as epileptologists, specialize in the diagnosis and treatment of epilepsy. Accurate diagnosis and immediate treatment for the many varieties of epilepsy are extremely important. Referrals to qualified specialists are available from the Epilepsy Society of Massachusetts, county and state medical societies, and teaching and community hospitals; seizure and neurology clinics are available in some areas.

We have found these resources to be very helpful for (1) referrals to medical and other human services providers, and (2) detailed information, especially re eligibility and funding, on all important federal and state programs that bear directly on the social, economic, rehabilitative, medical, educational and housing needs of individuals and families:

1) Directory of Health Resources in Massachusetts, 1976. Prepared by United Community Planning Corporation (UCPC) and compiled from data collected by the Office of Health Statistics, Mass. Dept. of Public Health. Order from UCPC, 14 Somerset St., Boston, MA 02108 ($9.75 per copy if payment accompanies order; $10.75 if billing requested). Lists homemaker services, home health care agencies, rest and nursing homes, residential facilities (including those specifically accepting epilepsy), hospitals and community medical and mental health/counseling clinics (including facilities with seizure and neurology services). 500 pages, very useable.
2) Encyclopedia of Selected Federal and State Authorizations for Services and Benefits in Massachusetts, 1976. Prepared by and available from the Office of Federal/State Resources (see entry under "Other State Agencies" in this handbook).

Two other useful resources are: Directory of Residential and Non-Residential Service Providers in Massachusetts, 1975, prepared by the Office of Federal/State Resources. This directory lists and defines over 5,500 service vendors and is kept up-to-date via computer listings--see entry on OF/SR for further information. Another resource is the "Select Geographical Directory of Epilepsy Facilities in Massachusetts" prepared in 1975 by the Epilepsy Society of Massachusetts; a slight misnomer as there are virtually no epilepsy facilities per se in the state, this directory lists in zip code order various medical and human services providers who are likely to be serving persons with epilepsy. Phone E.S.M. for referrals from this source (617-267-4341).

Since so few services are specific to epilepsy, there is no substitute for vigorous researching, hunting and even "fighting" on behalf of a particular individual in need of service. Appropriate service or placement, beyond the strictly medical, will depend more on the particular needs of the person than on the isolated fact that he has epilepsy. We hope that this handbook will provide the background that will facilitate the provision of good services.

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* The American Board of Psychiatry and Neurology, a member of the American Board of Medical Specialties, certifies as diplomates those neurologists who have achieved a high level of competence in their field, as attested to through adequate preparation in accordance with established educational standards and the passing of comprehensive qualifying examinations.

C O N T E N T S

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C O N T E N T S (continued)

S E C T I O N I

EPILEPSY IN MASSACHUSETTS: AN OVERVIEW OF PROGRAMS & LAWS

I. Services Specifically for Epilepsy

A. Massachusetts Department of Public Health - Epilepsy Program
39 Boylston Street
Boston, MA 02116
617-727-5822
Director: Edward Lichtenstein
Community Coordinator: Jody Jenkins

In 1968 the Legislature established in the Department of Public Health "a program for the care, treatment and medical rehabilitation" of persons with epilepsy in Massachusetts. The Epilepsy Program includes:

1. Clinical services for persons under age 21

DPH funds or provides certain neurological services for children and teenagers who have or are suspected of having epilepsy. Under these programs, one diagnostic visit is available without charge to anyone under 21, after appropriate registration. On-going services are offered at no or minimal charge, depending on the family's ability to pay. Consult Attachment H for further information on services.

In the greater Boston area, out-patient seizure/neurology clinics at several major hospitals cooperate with DPH's Epilepsy and Handicapped Children's Programs. These arrangements offer financial assistance to families who need help meeting medical care costs for a child with epilepsy. For a list of cooperating hospital clinics and contact persons, see Attachment H.

Outside the Boston area, DPH runs six community-based pediatric neurology clinics, in:

Northeastern Mass.	(Tewksbury)
Southeastern Mass.	(Lakeville)
Cape Cod	(Pocasset)
Central Mass.	(Southbridge; Webster)
Western Mass.	(Pittsfield)

Refer to Attachment H and/or contact the Epilepsy Program for information on referral procedures, application, description of services offered or covered, etc., at both the Boston hospitals and the DPH clinics.

2. Anti-convulsant medication program

This program, which pays pharmacy bills for prescribed seizure control medications, is designed for Massachusetts residents with limited financial resources whose medication expenses are not covered by Medicaid or a private health insurance plan. Contact the Epilepsy Program for an application form.

3. Community and education services

Contact the Community Coordinator of the Epilepsy Program for:
--Information and referral (including limited telephone counseling; liaison with public and professional agencies and services)
--Public and professional education programs, arranged to meet the needs of any group of staff, etc.
--Materials (pamphlets and articles in limited quantity; films on day-loan)

B. Voluntary Associations

The following private Massachusetts agencies are specifically concerned with the problems of epilepsy. They offer, among other services, information about this widespread disorder and referral to numerous public and private services.

1. Epilepsy Society of Massachusetts, Inc. (a statewide organization)
3 Arlington Street
Boston, MA 02116
617-267-4341

Executive Director: Edward B. Shaw
Client Services: Barbara Wilson
Program & Office Coordinator: Carol Perry
Consumer Service Agent: Linda MacNevin

A private, non-profit organization, ESM acts as a spokesman and advocate for people with seizure disorders, working to promote individual and community support; to this end it sponsors numerous programs and activities for people with epilepsy, members of the general public, and professionals. ESM provides informational literature, speakers, films, educational and self-help programs, and information/referral services. All services of the agency are free of charge and open to all interested persons. ESM is funded in part by Massachusetts Bay United Way and in part by private contributions and donations, and by its membership program.

Membership in ESM and the national organization with which it is affiliated, the Epilepsy Foundation of America (EFA), offers regular state and national newspapers (ESM's Torchbearer and EFA's National Spokesman), and options for the purchase of low-cost drugs through a mail-order pharmacy and low-cost group life insurance (for employed members). A separate membership in ESM is also available; contact the office for particulars.

ESM cooperates with other private and public agencies, among others, the Massachusetts Rehabilitation Commission, the Mass. Dept. of Public Health, the Division of Employment Security-Office of Special Services, the Office of Federal/State Planning and the Mass. Developmental Disabilities Council. It is a member of the Mass. Health Council. ESM refers to board-certified neurologists (including epileptologists*) and to sources of inexpensive anticonvulsant medications and health and life insurance.

2. Local Epilepsy Organizations

The organizations listed below vary greatly in size, organization, and services and--as with ESM above--seek volunteers and local support from people with epilepsy and their families, interested professionals and community members. Contact the group in your area to find out about programs and activities, or check with ESM for news of new local group development.

a. Epilepsy Society of Greater Boston, Inc.
(address, staff and phone same as for ESM, above)

b. Epilepsy Society of Merrimack Valley, Inc.
Contact: ~~Dick McCarthy~~ Armand La France
~~% Mass. Rehabilitation Commission~~ 11 Lawrence St. Rm. 412
~~499 Essex Street~~
Lawrence, MA 01840 Phone: ~~617-685-1731~~ 686-3951

c. Epilepsy Support Program - Concord area
(an ad hoc group offering self-help and informational meetings)
Contact: Elise Surko (861-8085) or Millie Ullman (275-1067)

d. Epilepsy Society of Greater Framingham
133 Lincoln St. (on the grounds of Union Hospital)
Framingham, MA 01701
617-872-5212 Executive Secretary: ~~Selma~~ Rosenberg

* An epileptologist is a physician, usually a neurologist, who specializes in the diagnosis and treatment of epilepsy.

e. Epilepsy Society of Worcester County, Inc. - Epilepsy Service Center
25 Winthrop St. (% St. Vincent Hospital)
Worcester, MA 01604
617-798-6243
Executive Director: Lois Kaplan
President: ~~Jerome Jacobs~~ Ralph Long

f. Epilepsy Society of Southeastern Massachusetts
Contact: Dr. Nelson Hastings
% St. Luke's Hospital
101 Page Street
New Bedford, MA 02740
Dr. Hastings' office phone: 617-993-5802
President: William Dougherty 617-992-0763 (eve.)

g. Greater Springfield Epilepsy Association, Inc.
718 State Street
Springfield, MA 01109
413-737-6672
Office Coordinator: Betty Grout
President: ~~Roger Gray~~
~~Vice-President:~~ Helena Harris (413-283-3411)

3. Epilepsy Foundation of America, Inc. (a nationwide organization)
1828 L Street, NW
Washington, DC 20036
203-293-2930
Executive Director: Mr. Jack McAllister
Director of Chapter Program Services: Mr. Lewis Strudler

A nationwide voluntary organization which operates through a network of approximately 160 state and local affiliated chapters (in Massachusetts, the affiliates are the Epilepsy Society of Massachusetts and the Greater Springfield Epilepsy Association), the Epilepsy Foundation of America (EFA) seeks to interpret the needs of people with epilepsy to the society at large. It produces informational materials, sponsors professional education programs and supports medical and social research, and maintains liaison with the federal government and with other major health voluntaries at the national level. It co-sponsors a membership program with local affiliated associations; for information, contact the Epilepsy Society of Massachusetts or the Greater Springfield Epilepsy Association.

II. Other Governmental Agencies and Programs Providing Services to People with Epilepsy

A. Commonwealth of Massachusetts

1. Agencies concerned with employment

a. Massachusetts Rehabilitation Commission
Administrative Offices and Epilepsy Program
296 Boylston Street
Boston, MA 02116
617-727-2184
Epilepsy Coordinator: Mr. Frank Nardo

The Massachusetts Rehabilitation Commission (MRC) is the state agency concerned with the vocational rehabilitation of disabled individuals, including persons with epilepsy. Eligibility requirements are met if:

1) a physical or mental disability is present (having epilepsy constitutes a "physical disability" for the purpose of eligibility requirements);
2) a substantial handicap to employment exists; and
3) vocational rehabilitation services may be expected to render the individual capable of engaging in a satisfactory, gainful occupation.

The following rehabilitation services, among others, may be provided:

--Medical, psychological and vocational evaluation to determine the nature and degree of disability and to assess work capacity
--Counseling and guidance to achieve vocational adjustment
--Medical, surgical, psychiatric and hospital care and related therapies to reduce or remove disability
--Vocational training in line with abilities, capacities and limitations
--Placement and follow-up

Local offices providing services are located in cities and towns throughout the state. For further information write or phone Mr. Frank Nardo, Coordinator of MRC's Epilepsy Program (617-757-2184), or contact the nearest area office (list below). Mr. Nardo is also available as a resource person should an epilepsy client or counselor have special concern, problems or complaints. Many area offices have recently designated one counselor as an "epilepsy resource person"; the client with epilepsy will not necessaril be assigned to this counselor, but the system provides a local source of specialized knowledge.

Massachusetts Rehabilitation Commission Area Offices

Boston 357-8137
141 Milk St.

Brockton 583-1530
196 Main St.

Brookline 739-9080
320 Washington St.

Cambridge 492-0360
2464 Mass. Av.

Concord 369-1963 or 1987
40 Stowe St.
Emerson School

Corrections 426-8555
80 Boylston, Boston

Fall River 678-9041
10 Purchase St.

Fitchburg 345-1713
76 Summer St.

Greenfield 774-2326
324 Main St.

Holyoke 536-8200
560 Dwight St.

Hyannis 775-6131
147 Falmouth Rd.

Lawrence 685-1731
499 Essex St.

Lowell 457-7544
97 Central St.

Lynn 593-6604
36 Exchange St.

Malden 324-7160
33 Dartmouth St.

Mattapan 288-4600
591 Morton St.
Dorchester

Milford 478-0700
3 Fayette St.

Natick 655-7500
83 Speen St.

New Bedford 993-6256
558 Pleasant St.

Norwood 769-5950
511 Washington St.

Pittsfield 499-2720
6 Clinton Av.

Quincy 471-1600
1431 Hancock St.

Rehab Services for the Deaf
80 Boylston St.
Boston 426-7224

Roxbury 442-5510
55 Dimock St.

Severe Physical Disability
Office 426-7250
80 Boylston, Boston

Southbridge 765-5968
922 West Main St.

Springfield 736-7296
16 Fort St.

Taunton 823-8141
30 Taunton Green

Worcester - City 754-1757
75B Grove St.

Worcester - Suburban
110 Lancaster St.
791-6301

Services of MRC are provided on a non-discriminatory basis, & without regard to race, creed, sex or national origin.

Client Assistance Project

In 1975 the Massachusetts Rehabilitation Commission initiated a special Client Assistance Project (CAP), which is designed to assure better rehabilitation services to MRC clients in the areas served by the Boston regional office (including the specialty services), the Metropolitan regional office (except the Concord and Natick area offices), and the Malden regional office. Any MRC applicant or client (present or former, with special emphasis on the severely disabled and multiply handicapped) in these geographical areas who is dissatisfied with any phase of his/her vocational rehabilitation program or lack of it may contact CAP for assistance in arranging for needed services. The Epilepsy Society of Massachusetts is one of several consumer organizations represented on CAP's Advisory Board.

Client Assistance Project
c/o Easter Seal Society
14 Somerset Street
Boston, MA 02108
617-227-9608
Director: Mrs. Sarah D. Ward

b. Division of Employment Security

The Division of Employment Security (DES) is the state agency concerned with assisting unemployed persons in their search for work. Persons with epilepsy may request assistance from a Specialist in Services to the Handicapped at any local placement office. (For further information on services to the handicapped contact Mr. Arthur DesRoches, Special Applicants Dept., at the Government Center headquarters: 727-6478) Applicants may be eligible for any or all of the services of DES to improve their employment prospects; these include employment counseling, occupational testing, training programs, and placement. DES is also responsible for administration of the Unemployment Insurance Program for the Commonwealth.

For information and services, contact the nearest placement office:

Athol	534 Main St.	249-3533
Attleboro	29 Park St.	222-1950
Boston:	Charles F. Hurley Bldg., Government Ctr.	
	Clerical and Sales	727-6420
	Professional & Managerial	727-6398
	253-255 Huntington Av.	
	Industrial-Service-Domestic	262-9500
Brockton	25 White Av.	586-8100
Cambridge	371 Green St.	547-7757
	727 Massachusetts Av.	547-7625
East Boston	68 Central Sq.	569-4200
Fall River	446 North Main St.	679-6421
Fitchburg	356 Broad St.	343-6461
Framingham	206-214 Howard St.	875-5238
Gardner	175 Connors St.	632-5050
Gloucester	18 Washington St.	283-4772
Greenfield	31 Federal St.	774-4361
Haverhill	38 Kenoza Av.	374-4753
Holyoke	227 South St.	536-1967
Hyannis	60 North St.	775-5800
Jamaica Plain	408 South Huntington Av.	522-4500
Lawrence	444 Canal St.	682-5217
Lowell	291 Summer St.	457-7641
Lynn	52-62 Market St.	595-2220
	172A Broad St.	595-6933
Malden	213 Main St.	322-8890
Marlboro	186 Main St.	485-2080
Milford	65 Congress St.	473-1985
New Bedford	618 Acushnet Av.	997-7831
Newburyport	15 Green St.	462-4494
Newton	290 Center St.	969-9470
North Adams	85 Main St.	663-3748
Northampton	29 Pleasant St.	584-2783
Norwood	17 Central St.	762-0354
Pittsfield	46 Summer St.	499-1793
Plymouth	15 Court St.	746-1850
Quincy	1433 Hancock St.	471-2750
Salem	118 Washington St.	745-1860
Springfield	1592 Main St.	785-1231
	501 State St.	781-3134
Taunton	72 School St.	824-5835
Waltham	14 Spring St.	894-4492
Ware	18 North St.	967-5941
Webster	562 Main St.	943-1240
Woburn	25 Montvale Av.	935-4654
Worcester	51 Mrytle St.	757-3813
Professional Service Center:	400 Totten Pond Rd., Waltham	890-7150
Apprentice Information Ctr.	408 So. Huntington Av., Jamaica Plain	522-4500

c. Department of Labor and Industries
Division of Industrial Safety
100 Cambridge Street - 11th fl.
Boston, MA 02202

Investigator: Tom Daley
617-727-3567

The Division of Industrial Safety of this Department is responsible for investigating charges of alleged employment discrimination against handicapped workers (state law, Section 24K of Chapter 129, prohibits discimination against handicapped persons--see Section III of this handbook on laws relating to employment). If a person is refused equal consideration in hiring or is dismissed from a job "solely because of his handicap" (epilepsy is interpreted as a handicap for the purposes of this and most other laws), he/she should document the circumstances of the incident as thoroughly as possible and contact Tom Daley who will initiate investigation. There is no charge for this investigation; the state will conduct hearings and prosecute, where appropriate.

If the employee or applicant is covered under federal anti-discrimination statutes (see III. B., Rehabilitation Act of 1973), Mr. Daley will refer to the appropriate federal official.

The Dept. of Labor and Industries is also responsible for setting and inspecting standards and compliance for safety and occupational hygiene, and for overseeing compliance with the state's workmen's compensation requirements.

(In regard to workmen's compensation insurance, it is worth noting that rates do not go up when an employer hires a person with epilepsy or any other handicap or disability. These insurance rates have no relation to the type of worker hired; but depend on the frequency and severity of accidents sustained by all workers in a given category of industry. There is therefore no basis for fear on the part of an employer that his insurance rates will go up if he hires a worker with epilepsy. --Ed.)

2. Agencies Concerned with Health and Social Services

a. Department of Mental Health (DMH)

DMH is the state agency responsibel for various programs and services relating to the care of those who are mentally ill or mentally retarded, as well as those with drug dependencies. Services range from institutional care to regional and local programs of diagnosis and treatment, rehabilitation programs, preventive pre-care, after-care services, program research and evaluation. DMH also delivers and funds prevention-oriented services to promote the mental health of the general population: of interest to persons with epilepsy are community mental health centers, which offer counseling and other social services.

Most of the seven major divisions of DMH have some impact on persons with epilepsy; the major effort and budget, however, are concentrated in the Division of Mental Retardation, which runs state schools for the retarded (almost 40% of the state school population has a diagnosis of epilepsy), regional centers, statewide pre-school programs, statewide infant home-teaching programs, community residences and day activity programs.

Like most state agencies, DMH administers programs and services through a network of regional and area (local) offices. Central administrative offices are located at 190 Portland Street, Boston, MA 02114 (Commissioner: Robert Okin, MD; 617-727-5600). For information, check the phone book or call the nearest regional office:

Region I	(Northampton)	415-727-6695
II	(Shrewsbury)	617-845-2131
III	(Waltham)	617-899-9560
IV	(Hathorne)	617-727-7024
V	(Medfield)	617-326-6470
VI	(Boston)	617-727-5795
VII	(Brockton)	617-584-5714

Editorial Comment:

Recent focus on "de-institutionalization" has revealed a scarcity of alternative community residences and day activity programs for individuals who do not require or benefit from traditional institutional settings but who do need supportive services and environment. Historically, some people with epilepsy have been institutionalized, many of these inappropriately. Before the era of modern anti-convulsants (phenobarbital dates from the turn of the century, dilantin only from the late 30's), seizure control was difficult if not impossible, making institutionalized placement and supervision of people with epilepsy sometimes necessary. The only drugs available in the 19th century for the control of seizures were the bromides, which also caused mental confusion and sluggishness. Some persons have been placed and kept in institutions because their epilepsy was compounded by or confused with mental illness or because they were assumed to be retarded. Indeed, until recently, epilepsy legally constituted grounds for involuntary commitment to state mental hospitals. Historically, the state facility for "epileptics" was Monson State Hospital, in Palmer; DMH no longer has specific institutions or programs relating to epilepsy. There remain, however, many persons with seizure disorders, in combination with other disabilities, in state institutions.

Helpful sources of information as regards DMH's role in community residences and other services for the retarded are: Ms. Linda Glenn, Associate Commissioner for Mental Retardation, and Mr. Don Anderson, Director of Programs and Services, in the Division of Retardation (727-5608). A helpful source of information as regards the mechanics of setting up a community residence which focuses especially on the needs of long-institutionalized individuals with epilepsy is Rachael Saganov, R.N., Executive Director of the Therapeutic Community. Therapeutic Community, Inc. (P.O. Box 42, Mattapan, MA 02126; 288-2572) is a small, private, non-profit organization funded largely by DMH which provides day programs, medical, psychiatric, and vocational support services, and residential placement for previously institutionalized persons with epilepsy and other conditions.

b. Department of Public Health (DPH)

DPH has three major areas of responsibility: (1) to provide actual health services through public health hospitals and community-based outlets; (2) to maintain surveillance over the health of the Commonwealth and to control disease through testing, vaccination, and analysis of trends; (3) to regulate health care facilities, consumer products and food and drug processing.

Through its regulatory and licensing functions, DPH is involved with the health care of most consumers in the Commonwealth. The Division of Family Health Services of the Department has a number of programs that serve individuals with seizure disorders: the Epilepsy Program (see Section I.A.) and the program of Services for Handicapped Children neurology and CP clinics; the program of Services for Multiply-Handicapped Children; pre-school nurser integrating handicapped and non-handicapped children; maternal and infant health programs; early intervention programs; medical assistance to DMH facilities. DPH's Institute of Laboratories has programs designed to prevent mental retardation (and frequently, seizures), e.g. PKU screening of newborns, mandatory rubella vaccinations, lead paint poisoning prevention.

c. Department of Public Welfare (DPW)

DPW is the state agency responsible for administering and/or providing numerous social welfare services and is responsible for coordinating federally reimbursed services to actual and potential welfare recipients. DPW has no programs specific to persons with epilepsy, but most if not all of its services are applicable. DPW accounts for 34% of the total state budget; major programs are Aid to Families with Dependent Children (AFDC), SSI (Title XVI-see Section II.B.1.a.), comprehensive social services (Title XX), General Relief (GR), Food Stamp Program, and Medicaid (Title XX).

The Medicaid* program pays for medical services for eligible individuals. A person can qualify for medical assistance, as either categorically eligible or medically needy. A recipient of public assistance (i.e., Supplemental Security Income-SSI, Aid for Families with Dependent Children-AFDC, or General Relief-GR) is termed categorically, i.e. automatically, eligible (GR recipients receive restricted categories of benefits). A "medically needy" person is someone under 21 and/or someone of any age who would be eligible for a public assistance program except that they have "too much" income: but, if that person's medical expenses are deducted from their income, he/she would have too little income left for personal support. Contact the Welfare Department's local service office (look in phone book under Massachusetts, Public Welfare) for information regarding specific criteria for eligibility and the extent and nature of services covered; there have been recent changes in both the eligibility and the coverage available to GR recipients.

The Department of Public Welfare also administers Title XX of the federal Social Security Act; this title provides for joint federal and state funding of social services (e.g., adult day care, homemaker services, protective care, transportation, etc.) for low-income persons. Services to be offered under Title XX are currently being set up and will vary from area to area; some are in existence already. Half of the clients to be served must be AFDC or SSI recipients. Citizen participation and review are mandated in the determination of which programs will be provided and by whom; agency response to planning and proposals is being sought. Goals are to encourage self-support, to help families to stay together, to reduce institutional care whenever possible and to arrange for appropriate institutional care when necessary. Many of the anticipated services will be of great assistance to persons with epilepsy, who should communicate to DPW and to local Title XX planning and review boards their interests and needs.

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* Medicaid should not be confused with Medicare, which is a medical insurance program for persons who receive Social Security benefits (see entry under "Social Security Administration").

3. Agencies Concerned with Children and Education

a. Department of Education (D.Ed.)
182 Tremont Street
Boston, MA 02111
Associate Commissioner, Division of Special Education: Robert Audette, Ph.D.
617-727-5440

In Massachusetts, the primary responsibility for providing public education belongs to the local cities and towns. The Commonwealth, however, plays a vital role in establishing laws, regulations, guidelines and services, administered through the Department of Education.

Under recent state legislation (Chapter 766), all children must be provided an education at public expense; children with "special needs" as determined after evaluation may be entitled to extra educational services between the ages of 3 and 21. Some children with epilepsy may be classified as having "special needs," either because of the medical condition or because of other (related or unrelated) problems that have implications for their educational requirements (see section III, A, c, for more detail on Chapter 766). The Division of Special Education has primary responsibility for implementing 766 and formulates regulations which prescribe plans for identification and evaluation of special needs children. Local school systems have the responsibility for funding, evaluating and providing services; this can be done either directly by the school system or through collaborative arrangements or on a contract basis.

The Division of Occupational Education is responsible for numerous programs of vocational and technical education, including arrangements for persons with disabilities. The Department of Education also offers an array of other services, including higher education, adult education, correspondance courses, curriculum development, etc., and is responsible for the certification of public school teachers. The Division of Special Education works in cooperation with other agencies, notably the Departments of Public and Mental Health, to arrange appropriate education for institutionalized or severely handicapped children.

b. Office for Children (OFC)
120 Boylston Street
Boston, MA 02116
617-727-8900
Director: Joyce Strom

Created by legislation in late 1972, the Office for Children is designed to coordinate services for all children up to age 16, or up to age 18 if they have special needs. The agency is charged with coordinating the various agencies delivering services and providing programs for children, monitoring existing services, and documenting gaps in services.

"Help for Children" is the information and referral/advocacy arm of OFC; offices exist in more than 30 communities (look in phone book, Massachusetts, Office for Children) to help children and their parents "get through the system." Help for Children is a good place to start for a parent or professional who wishes to locate services of any nature for a child or teenager, or to get help cutting through bureaucracy and red tape.

OFC has developed local citizens' councils to aid in planning responsive and effective programs. It is responsible for setting standards for and licensing all children's services.

4. Other State Agencies of interest to Persons with Epilepsy

As stated in the introduction, virtually every agency will have impact on people with epilepsy because of the large numbers of people with epilepsy throughout the general population. Increasingly, however, those agencies having responsibilities toward handicapped citizens will be serving persons with epilepsy as well as persons with more visible or traditional handicaps--if people with epilepsy and their advocates seek such services and coordinate their search with other disability groups. Among the many state agencies not mentioned in this handbook, those listed below should be of service to some people with epilepsy who may have problems with making practical living and transportation arrangements.

a. Department of Community Affairs (DCA)
100 Cambridge Street - Room 1404
Boston, MA 02202 Phone: 617-727-7765

DCA is responsible for state programs in the areas of housing, local affairs, and social and economic opportunity. The agency is organized in three principal divisions:

1) Community Development 727-7130
   a) Administers programs in the areas of state-aided low-rent housing; relocation and housing appeals;
   b) Administers Chapter 812 of the Acts of 1971. which mandates that 5% of all housing for the elderly be reserved for individuals with physical disabilities, regardless of age;
   c) Administers Chapter 689 of the Acts of 1974, which provides 10 million dollars for housing for individuals with disabilities, through the Bureau of Housing for the Handicapped.
2) Community Services 727-7001
   a) Responsible for planning in local communities and delivering community development-related services to local governments and regional agencies;
   b) Solves zoning problems in general, and as they relate to community residences for the developmentally disabled;
   c) Finances development of community residences, works with local housing authorities which own the buildings, and contracts with the sponsor for management and maintenance.
3) Social and Economic Opportunity 727-7004
   a) Provides tenant services and advocacy for tenants;
   b) Participates in job training and a mini-employment service center;
   c) Assists federally-designated anti-poverty agencies.

b. Executive Office of Transportation and Construction
1 Ashburton Place - 16th fl.
Boston, MA 02108 Phone: 617-727-7680

Since individuals with incomplete seizure control are not legally eligible for drivers' licenses, the availability of mass transit and other forms of public transportation, and in some instances specialized personal transportation services, is of great importance.

EOTC serves as a link between the governor and the five agencies (Dept. of Public Works, Mass. Aeronautics Commission, Mass. Port Authority, Mass. Turnpike Authority, and Mass. Parking Authority) that come under the jurisdiction of this Secretariat. EOTC's statewide Transit Analysis and Technical Assistance Program administers a program for elderly and handicapped persons, and attempts to coordinate state agency funding for specialized transit services for individuals who are mobility-impaired.

c. Office of Federal/State Resources
State House - Room 527
Boston, MA 02133
617-727-4178
Director: Doris Fraser, Ph.D.

and

Mass. Developmental Disabilities Council
McCormack Bldg. - 21st fl.
1 Ashburton Place
Boston, MA 02108
617-727-6374
Executive Director: Glenn Loveland, Ph.D.
Chairman: Paul Jameson, Esq.

The Office of Federal/State Resources is the state agency responsible for developing a comprehensive state plan for meeting the current and future service needs of developmentally disabled citizens. The "developmentally disabled" includes persons substantially handicapped by mental retardation, epilepsy, cerebral palsy and/or autism. OF/SR operates under the supervision of the Massachusetts Developmental Disabilities Council, which is a consortium of public and private agencies, consumers and providers related to developmental disabilities, appointed by the Governor.

OF/SR is additionally responsible for developing designs for implementing comprehensive and more specific goal-oriented plans, and for administering Federal P.L. 94-103 funds available under the Developmental Disabilities Services and Facilities Construction Act (see entry under Laws, III, B. 4).

The Mass. DD Council is responsible for monitoring and evaluating the implementation of the plan and administration of funds, and is separately responsible for advocating the implementation of plans and other actions which will benefit the developmentally disabled.

The Fiscal Year 1977 "State Plan for the Provision of Services and Facilities for Persons with Developmental Disabilities," prepared by the DD planning staff of OF/SR and reviewed and approved by MDDC, fully describes the functions of these two agencies and provides a useful overview of existing programs and planning procedures. Attachment 5.2B(a) consists of the first breakout this writer has seen of the estimated prevalence of persons substantially disabled by epilepsy, district by district (1970, 1975, and 1980), in Massachusetts.

OF/SR has recently published an enormously useful document for those who wish to unravel all the state and federal programs providing services to the developmentally disabled--funding mechanisms and eligibility requirements, etc. for programs such as SSI, Medicaid and the like. The Encyclopedia of Selected Federal and State Authorizations for Services and Benefits in Massachusetts-1976 outlines thoroughly every governmental program which involves money appropriated for this population.

OF/SR has recently published an exhaustive Directory of Residential and Non-Residential Services Providers in Massachusetts (1975), which defines over 100 legally established types of service providers and lists over 5,500 actual service vendors organized by geographical districts and "type" of provider. The final section of the Directory is a comprehensive listing of state agency resources, including names, addresses and phone numbers of administrative personnel in central and local offices.

The 935-page Directory is on sale for $15 at the State Book Store, Room 116, State House, Boston. The book may be picked up or orders will be processed by mail or phone (617-727-2834). If the Directory is to be mailed, there is an additional $1 postage and handling fee. Mail orders should be prepaid; write check payable to the "Commonwealth of Massachusetts." For further information regarding the Directory and training programs available in its use, contact OF/SR.

B. Federal

1. Social Security Administration 617-423-3700

There are two separate programs with disability provisions that may apply to a person disabled by epilepsy or by epilepsy plus another disability. A disabled individual can receive benefits from one or both programs simultaneously. Many of the medical requirements for establishing disability are similar under the two programs (SSI and SS-Disability), but the programs and their eligibility requirements are not the same. It sounds confusing, but the information clerks at the regional social security office are very helpful (phone number above). For a summary of when epilepsy constitutes grounds for a determination of disability, see the entry following part "b" of this section. For more general information on these and all other social security programs, call 617-423-3700.

a. Supplemental Security Income (SSI)

This program was created recently to replace federal grants for aid to the blind, aged and disabled, previously administered by state governments; it represents an effort to develop national standards. It is a program based on financial need (as well as disability); it is not a right.

A person of any age, disabled and with limited financial resources, may be eligible for SSI. A "disabled person" is one who has a physical or mental impairment which prevents him/her from doing substantial work and which is expected to last at least 12 months and/or result in death; or, in the case of a child under 18, an impairment of comparable severity (a child may be judged disabled if his/her impairment greatly interferes with normal growth and development). Financial eligibility is determined by a complex formula. Parents income and resources are considered in the case of a child; an adult, however, even if living with parents or relatives, is considered on the basis of his own resources as "living in the household of another." A person who is working may still be eligible, if his financial resources and earning capacity are limited; applicants to SSI are automatically referred for vocational rehabilitation evaluation.

SSI assistance, no matter how small the amount of the monthly check, entitles the recipient to Medicaid benefits. Thorough documentation of disability is essential, as is full disclosure of financial assets. Disability may be determined on the grounds of epilepsy alone (when the seizures are so severe or frequent that remunerative work is not possible or is very limited--see general guidelines below) or epilepsy in combination with other conditions (e.g. cerebral palsy, mental retardation, etc.). In Massachusetts, the agency charged with certifying disability is the Massachusetts Rehabilitation Commission. A prospective applicant can phone the main office of the Social Security Administration to get a "rough reading" of financial eligibility (617-423-3700); the application process is then conducted via the nearest local office. They will assist the applicant to obtain a social security number if he/she doesn't have one.

The SSI program is therefore well worth looking into if income and resources and low and if disability is severe and long-term. There are formal appeals procedures, at which an applicant may have assistance and representation; it is worth appealing a rejection, particularly one on medical grounds, as many are reversed. The single greatest error many adult applicants make is not providing a thorough medical documentation of disability. Perseverance is important too; the process may be long, but if an applicant is approved it is retroactive to the first of the month of the initial application.

If the Social Security district office is unable to help or cannot straighten out a problem, an applicant may contact the "social security ombudsman

service" for eastern Massachusetts (this is the first service of its kind in the country) at 617-223-0402.

If problems arise such that an applicant desires outside legal/technical assistance, he/she may contact the SSI Advocacy Center. The Center, funded in part by the state Department of Elder Affairs and in part by the Mass. Developmental Disabilities Council, is located at 2 Park Square, Boston. It is associated with the Mass. Law Reform Institute, and assists current and prospective recipients of SSI through advocacy and legal assistance. Phone: 800-882-2019 or (local) 482-2307.

b. Social Security Disability Assistance (SSDA)

The Social Security disability insurance program provides benefits for individuals who have worked long enough or recently enough in employment covered by social security and for impaired widows, widowers, and children of workers who have become disabled, died or retired.

A disabled individual or his family may apply for social security disability payments by contacting a local social security office. Before payments can be made, medical evidence of the person's disability must be provided along with other proof, such as age and family relationship. When an individual applies for social security benefits, he will be considered for vocational rehabilitation services by the Mass. Rehabilitation Commission and must accept its recommendations before payments will be made. If an applicant receives a denial notice for disability benefits, it does not mean that a decision has been made about eligibility for any other type of social security benefits such as SSI (see above). If the application is denied, the person may submit new evidence concerning the disability. If the person feels that denial of his case was incorrect, an administrative hearing may be requested.

Here are some GENERAL GUIDELINES about QUALIFYING FOR DISABILITY BENEFITS on the grounds of EPILEPSY. (Source: Samuel E. Crouch, Acting Director of the Bureau of Disability Insurance of the Social Security Administration, quoted in the September 1975 National Spokesman, monthly newspaper of the Epilepsy Foundation of America, Washington, DC.)

"To meet the disability requirement, an individual must have a medically determinable impairment that has prevented or is expected to prevent him from engaging in his usual work activity or any other substantial gainful work for a continuous period of at least 12 months. Since the social security law provides that the definition of disability applies to all medically determinable conditions, disability claims from persons with epilepsy are given the same consideration as those from other individuals.

"Generally, an individual with epilepsy will meet the disability requirement if he has major motor seizures (loss of consiousness and convulsions) substantiated by clinical findings and occurring more frequently than once a month in spite of prescribed treatment.

"He will also usually qualify if he has minor motor seizures (alteration of awareness or loss of consciousness) substantiated by clinical findings and occurring more frequently than once a week in spite of prescribed treatment.

"Where adequate seizure control is obtained only with unusually large doses of medication, consideration is given to any impairment resulting from the side effects of this medication. Consideration is also given to impairment-related work restrictions, such as avoiding work around moving machinery.

"An individual with epilepsy not as severe as described above might still qualify for benefits if he has an additional impairment or if his condition, considering his age, education and work experience, nonetheless prevents him from engaging in substantial gainful activity."

c. Medicare

Medicare is a health insurance program of the federal government administered by the Social Security Administration.

It is a program for people 65 years of age and older and some people under 65 and disabled. Medicare provides two types of medical insurance, known as Part A and Part B. Part A is a hospital insurance plan and provides basic protection against the costs of in-patient hospital care, post-hospital extended care and post-hospital home health care. Part B is medical insurance which provides supplemental protection against costs of physicians' services, medical services and supplies, home health care services, out-patient hospital services and therapy, and other services.

Disabled persons under 65 who have been receiving Social Security Disability checks (not SSI payments - SSI recipients are covered by Medicaid, a state administered medical assistance program; see entry under "Mass. Dept. of Public Welfare") for a 24 month period will automatically receive Medicare benefits, along with continuing Social Security payments, in the 25th month. Medicare benefits cease if the Social Security Disability payments end before the 65th birthday. They would, of course, resume at age 65.

Contact the regional Social Security office with any questions concerning Medicare benefits: 617-423-3700.

2. Armed Services and Veterans Administration

a. Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)

Dependents of active duty members of the Uniformed Services, retired members and their dependents, and surviving dependents of deceased active or retired members are entitled to certain medical care benefits. For information on this program and application procedures, contact the CHAMPUS advisor at any uniformed service hospital. In Massachusetts, V.A. hospitals are located in Bedford (617-275-7500), Boston (617-232-9500), Brockton (617-583-4500), Northampton (413-781-2397), and West Roxbury (617-323-7700).

b. Civilian Health and Medical Program of the Veterans Administration (CHAMPVA)

CHAMPVA is a health and medical care plan, similar to CHAMPUS in its provisions, provided for dependents (spouse, children) and survivors of veterans who are determined by the Veterans Administration Eligibility Clerk to be totally and permanently disabled or who are deceased as a result of a service-related injury.

If determined eligible by the VA, a child receives benefits until age 18. However, an individual 18 years of age or older but incapable of self-support because of a mental or physical incapacity that existed prior to age 18 is entitled to benefits indefinitely or until he or she marries.

c. Education for Wife, Widow, or Sons and Daughters, of the Disabled Veteran

If a veteran is rated by the VA as 100% permanently disabled from service-connected causes, his spouse and children between 18 and 26 years of age are eligible to receive educational assistance. Counseling is available to the wife and children to help plan the educational or vocational program. Special attention is given to the selection of training programs for handicapped children. Contact the Veterans Administration Education Assistance Dept: general information number for New England: 617-227-4600.

3. National Institute of Neurological and Communicative Disorders and Stroke (NINCDS)

This branch of the National Institutes of Health (a division of the U.S. Department of Health, Education and Welfare) funds and conducts basic and clinical research on the epilepsies and other neurological conditions and publishes scientific and public information literature.

Epilepsy Branch - Neurological Disorders Program
N.I.N.C.D.S.
National Institutes of Health
Bethesda, MD 20014
Director: J. Kiffin Penry, MD

4. Developmental Disabilities Services and Facilities Construction Act of 1971

Though technically an amendment to earlier mental retardation legislation, this law (P.L. 91-517) considerably enlarges the target population to include several neurological conditions. A "developmental disability" is a condition hampering an individual's functioning. This condition of slower development and/or lessened ability to deal with one's environment may arise from one or more of the following: autism, cerebral palsy, epilepsy, mental retardation or other neurological malfunctioning of the individual. The disability is called developmental when it originates before the individual is 18 years of age, and when the condition is expected to continue indefinitely. The disability is also usually associated with some difficulty in learning, in social adjustment, and in economic productivity.*

The Act provides funding in two major areas; it is administered in Massachusetts by the Office of Federal/State Resources. Title I authorizes grants for "planning, provision of services, and construction and operation of facilities for the developmentally disabled." Title II authorizes "construction, demonstration and training grants for university-affiliated facilities." Massachusetts' allotment of funds for Fiscal Year 1974 was $717,000.

1975	692,915
1976	898,984
1977	717,164

* Most individuals with epilepsy are not disabled by their epilepsy to the extent described in this definition. The inclusion of epilepsy under the "developmental disabilities," however, opens sources of public funding that benefit all those "disabled" to whatever degree by their neurological handicaps.

5. National Commission on the Control of Epilepsy and Its Consequences

Section 264 of the Health Services Act of 1975 calls for the Secretary of HEW to appoint a 9-member national commission to conduct a one-year study on epilepsy. The Commission is charged to:

1) make a comprehensive study of the state of the art of medical and social management of the epilepsies in the United States;

2) investigate and make recommendations concerning the proper roles of federal and state governments and national and local and private agencies in research, prevention, identification, treatment and rehabilitation of persons with epilepsy;

3) develop a comprehensive national plan for the control of epilepsy and its consequences based on the most thorough, complete, and accurate data and information available on the disorder; and

4) transmit to the President and the Committees on Labor and Public Welfare of the House of Representatives, in the spring of 1977, a report of the Commission findings and recommendations.

Two members of the 9-person Commission, appointed by the Secretary of HEW, are from Massachusetts; they are:

Mrs. Ellen Grass
77 Reservoir Rd.
Quincy, MA 02169
617-479-5726

Ms. Clara Tubby
39 Clover St.
Belmont, MA 02178
617-484-2120

A northeast regional meeting of the Commission was held in New York City on October 7-8, 1976. A site visit to Massachusetts was conducted by a Commission task force on residential facilities on October 14-15. Four members of this task force (Dr. Dybwyd, Dr. Morreau, Mrs. Reuben and Ms. Turner) visited Therapeutic Community, Inc., a Boston-based private non-profit organization providing comprehensive community residential and day programs for previously institutionalized persons with seizures; and Monson State Hospital, historically the state's institution for epileptics, now a DMH retardation facility currently serving a very high percentage of individuals also with epilepsy.

It is hoped that a comprehensive national plan will favorably influence the direction of federal epilepsy programming and funding in the years to come.

Individuals wishing to contribute to the work of the Commission may contact the representatives from Massachusetts or the Commission office:

National Commission for the Control of Epilepsy and
Its Consequences
Federal Building - Room 1C-08
7550 Wisconsin Av.
Bethesda, Maryland 20014
Executive Director: Richard L. Masland, MD
Deputy Executive Director: Ms. Patsy Owens

6. Civil Service - Federal

There has been recent progress as regards opportunities for persons with epilepsy to be employed in the federal civil service.

Question 29, which once asked all applicants to state on the initial application form (171) whether they had epilepsy or any of a collection of medical conditions, need no longer be answered on that form. The information must still be given, but is now submitted in confidence to the medical officer further along in the job-seeking process. Individuals who can obtain a physician's opinion that their seizures are under reliable long-term control have a better chance for Civil Service employment than ever before. The Civil Service Commission will consider the employment of persons with controlled seizures to operate government vehicles (though not during rush hours!).

The person who still has seizures and who has had difficulty in establishing a prior work record may be eligible (not automatically but on an individual basis) for the Civil Service's special handicapped appointment procedures (which are outlined on pages 306-13 of the Federal Personnel Manual). These procedures are designed to bring handicapped persons into Civil Service employment without making them go through the competitive procedures.

One such special procedure is the 700-hour temporary trial appointment. This gives severely handicapped people a 4-month trial period of Civil Service appointment during which they have a chance to prove their ability and get some job experience at the same time. Under the program, jobs can be developed to conform to this skills of the person, rather than the other way around. Having epilepsy does not <u>per se</u> qualify one for the "severe disability" category; however, each case is considered on an individual basis, so that some people disabled by epilepsy will be eligible for excepted appointments.

(Note: The application for Massachusetts <u>state</u> employment does <u>not</u> ask whether the candidate has a present or past history of seizures.)

C. Greater Boston

1. Massachusetts Bay Transportation Authority (MBTA)

The "T" offers half-fare rides during off-peak hours to people with special transportation needs, including people with epilepsy. A photo identification card, available for a 50¢ fee, is required; the applicant will be asked to provide certification of disability by a registered physician or an authorized agency. For applicants with epilepsy, the Epilepsy Society of Massachusetts will provide such certification free of charge; the Mass. Rehabilitation Commission will certify its clients; or one may obtain the certification from one's physician. (For the purposes of this service, the MBTA defines "disability" to include all those persons with epilepsy.)

For details, certification forms, and an appointment, phone the MBTA Office of Special Needs, at 722-5123.

(The following transportation services, while not run by public agencies, are worthy of mention in that they may be useful to the person with epilepsy:

--The "helping hand" program of the Greyhound Bus Lines allows a handicapped person to have a traveling companion for the price of one ticket. A child or an adult who might have an epileptic seizure, could be eligible for the "helping hand" program. A letter from a physician is required stating: (1) that the person has epilepsy, and (2) that the traveling companion would be able to provide the needed assistance were a seizure to occur.

--T.H.E.M. Inc. (Transportation for the Handicapped and Elderly in Massachusetts) is a private non-profit corporation interested in the transportation problems of the elderly and the handicapped. They operate a fleet of vehicles and an information/referral service to help with everyday problems such as transportation, housing, education, employment, aids to daily living and numerous other subjects.

T.H.E.M., Inc.
141 Milk Street - Suite 1101
Boston, MA
617-542-5461)

2. Tel-Med Service

This is a free telephone health library offering taped information in English and Spanish on numerous health problems, including epilepsy. Originally established by the Boston Department of Health and Hospitals, this service is now supported by Blue Cross/Blue Shield. Tape #125 is general information on epilepsy; tape #109 gives first aid advice for handling epileptic convulsions. Phone 482-3333.

III. Laws Pertaining to People with Epilepsy

There are very few remaining references specifically to epilepsy in state and federal laws. The following commentary, written by Boston attorney Donald Freedman, provides an introduction to epilepsy and the law:

> It is becoming increasingly evident in the law that whether a person has or has not epilepsy creates neither special legal liabilities nor special legal rights for the individual. Whether the issue is the right to marry, to make a will, drive a car, or to obtain workmen's compensation benefits, the courts are saying with increasing frequency, in effect, "So what, he has epilepsy. That doesn't make any difference in itself. Tell me what he does."
>
> Whether this development is to be applauded or feared by advocates will likely never be resolved. For example, while we may applaud the judge who refuses to hear evidence of a parent's seizures in determining whether they are fit parents, are we willing to lend the same support to the criminal law judge who refuses to give special treatment to a teenager with epilepsy who is arrested for a street crime.
>
> Second, the law increasingly reflects the realization that the term epilepsy incorporates a great diversity of differing conditions, and more importantly, a tremendously variable range of disability, from total disability requiring round-the-clock protective care and treatment, to the absence of any significant disability at all. The most specific manifestation of this trend is the increasingly frequent legal requirement of individualized evaluations, whether for disability assistance, special education placements, or the securing of a driver's license.
>
> Third, the law increasingly reflects the view that any disabling effects of epilepsy are subject to change, and that the vast majority of seizure disorders are controllable through medical intervention. Where the fact of a seizure disorder causes some disqualification for the individual--as for a driver's license--the finding is now usually subject to periodic review or re-opening at a later time, on the assumption that the person's condition may change.
>
> In conclusion, then, we might state as a general proposition that the law is increasingly reflecting the view that people with epilepsy are just that: PEOPLE, with epilepsy. As people they must not be deprived of the civil and human rights that we all possess. (Legal questions may be addressed to Donald Freedman, Esq., c/o Epilepsy Society of Massachusetts, 3 Arlington St., Boston, MA 02116.

A. State Laws Pertaining to Epilepsy

Until recently, there were hundreds of references to epilepsy and epileptics in state laws. (There are now only three, and only two of these are functional--see references below.) These historical references classified "epileptics" somewhere among or in between the mentally ill and the mentally deficient (in earlier days referred to as the insane and the feebleminded); other references linked epileptics to "persons addicted to the intemperate use of narcotics and stimulants" and "dipsomaniacs" (in modern parlance, drug addicts and alcoholics). Major reform of mental health legislation governing grounds and procedures for commitment to retardation and psychiatric facilities has removed all such archaic and unfortunate references. Philosophically and legally, state responsibility for the treatment of epilepsy *per se* has shifted from the Department of Mental Health (where, historically, it was viewed as primarily a psychiatric problem or a condition related to retardation) to the Department of Public Health (where it is viewed as a prevalent medical disorder).

1. Specific References to Epilepsy in the General Laws of the Commonwealth

The following references are "on the books" as of April 1977:

a. Law establishing the Epilepsy Program in the Massachusetts Department of Public Health (Chapter 685, Section 4G) (1967)

"The Department shall establish, in one or more institutions under its control, a program for the care, treatment and medical rehabilitation of persons suffering from epilepsy and shall disseminate such information relative to the management of convulsive disorders as it considers proper. The Department may accept for such purposes and for research into the causes of convulsive disorders any special grant of money, services or property from the federal government or any of its agencies or from any foundation, organization or medical school.

"The Department shall cooperate with the Massachusetts Rehabilitation Commission in developing vocational rehabilitation programs for epileptics."

b. Amendment establishing the Epilepsy Program in the Massachusetts Rehabilitation Commission (paragraph "F", added in 1965)

"It (Massachusetts Rehabilitation Commission) shall establish and operate a program for the vocational rehabilitation of epileptics, supervised by a supervisor in education to be appointed by the Commission."

c. Epilepsy as constituting grounds for suspension or revocation of a barber's license (Chapter 418, Section 87L) (1931)

Note: Recent efforts to eliminate this provision have been successful. Though the law remained on the books as of late 1976, the state board responsible for the licensing of barbers agrees that the restriction is inappropriate and it has instituted requirements for applicants with epilepsy that are similar to those of the Registry of Motor Vehicles.

Ed. Comment: There are <u>no statutes</u> or regulations specifically pertaining to people with epilepsy <u>in the following areas:</u>

--Adoption: Statutes do not cite epilepsy as a basis for adoption annulment.
--Arrest/Search: Statutes do not require law enforcement officials to search for emergency medical identification on persons subject to arrest. However, training manuals for new law enforcement recruits recommend looking for medical identification devices.
--Institutionalization: Epilepsy is not mentioned in statutes pertaining to admission.
--Marriage: Marriage for persons with epilepsy is not restricted.
--Reportability: Epilepsy is not required to be reported to state agencies.
--State Education: The state's public higher education applications do not inquire as to a past or present history of epilepsy.
--State Employment: The application for state employment does not ask whether the candidate has a present of past history of seizures.
--State Identification: There is no official state-issued identification card other than a driver's license.
--Sterilization: Persons with epilepsy are not subject to involuntary sterilization.

2. Laws and Regulations with Relevance to People with Epilepsy

a. Licensing of Motor Vehicle Operators - Registry of Motor Vehicles

There are no state laws that refer specifically to qualifications for a person with epilepsy applying for a driver's license. The Registry of Motor Vehicles has established regulations pertaining to "people with special circumstances." The epilepsy regulations were drafted by a panel of neurologists some years ago and re-approved recently by a Highway Safety Medical Advisory Board.

The regulations require that an individual with epilepsy be seizure-free for 18 months before applying for his first driver's license. The applicant must then furnish the Registry with a letter from his or her neurologist giving the date of the last seizure, the type of medication (if any), and the neurologist's recommendation that a license be granted. After the license is first granted, the driver must supply subsequent letters from the neurologist every 3 months. After a period of successful driving, there is a process for amending the time period between letters to 6 or 9 months, and then up to 1 or 2 years. If a driver has a seizure while possessing a license, the Registry asks him to surrender his license for 6 months and then to submit another letter. When a routine is established, the driver signs an agreement stipulating the frequency of the letters and stating that he will refrain from drinking alcoholic beverages.

The purpose of the Registry's regulations is to screen out people who are possible safety hazards. A question on the back of the application form inquires specifically about a history or condition of epilepsy, seizures, fainting spells, blackouts, etc. It is the responsibility of each applicant or driver to inform the Registry of any seizures he has had in the past or presently experiencing. Receiving or retaining a license under false pretenses is illegal and disqualifies the operator from insurance coverage.*

The basic rules above are not always rigidly applied; the Registry is willing to be flexible and make changes in the waiting periods if the neurologist recommends it. A medical review board is available to consider complaints and special circumstances.

---

* In Massachusetts, auto insurance rates bear no relation to the medical condition of the applicant. Therefore, a driver with epilepsy will not be charged higher rates because of his condition.

b. Employment

1) Discrimination vs. handicapped workers

Following is the text of the state law prohibiting discrimination against handicapped workers (Chapter 149, Section 24K; enacted 1972):

"Whoever, personally or by an agent, shall dismiss from employment or refuse to hire, solely because of his handicap, any rehabilitated handicapped person who possesses the physical and mental capacity to perform the functions required by said employment shall be punished by a fine of not less than twenty-five nor more than two hundred dollars." *

Cases of suspected discrimination on the grounds of epilepsy or other handicap should be reported to the Massachusetts Department of Labor and Industries; see entry #7 under "Other Governmental Agencies and Programs." (see page__). An investigator will look into the case; even though the fines under this statute are low, the threat of prosecution by the Commonwealth encourages many employers to re-examine their practices.

2) "Second Injury" Law (Chapter 152, Section 37)

This law was greatly liberalized in January 1, 1974. Its basic components, which provide for insurance compensation coverage, partly at the Commonwealth's expense, after workmen's compensation benefits have run out, are: (1) a known physical handicap, impairment, disease, congenital condition, etc. (such as epilepsy) must have existed before the on-the-job injury (the employer, however, does not have to have been informed of the condition--it just has to be medically established that the condition existed); (2) the pre-existing condition plus the job-related injury must result in a disability which is substantially greater than would have resulted from the job injury alone; (3) second injury fund reimbursement from the Commonwealth begins after a 2 year period (this period being that covered by workmen's compensation insurance); from that time, 50% of the cost is bourne by the Commonwealth from the "second injury fund."

(Ed. Comment: This law has relatively little relevance to most workers with epilepsy, as it covers only those few situations where a worker's pre-existing epilepsy is significantly worsened as the result of a job injury; for example, when a traumatic head injury increases the frequency or severity of seizures. If an injury occurs either as a result of a seizure or completely independent of the epilepsy, that does not result in a worsening of the epileptic condition, normal benefits through workmen's compensation are applicable and the second injury fund would not apply. For further information, contact Mr. Al Horrigan or Mr. Charles Murphy of the Commonwealth's Industrial Accident Board: phone 727-3436.)

Editorial Note: Massachusetts has no specific anti-discrimination provisions for the handicapped in the areas of property ownership, housing and public accomodations.

* A "beefed up" version of this law has been filed as a bill for consideration by the 1977 session of the Legislature.

c. Special Education - Chapter 766

Under recent state legislation ("Chapter 766"), all children must be provided an education at public expense; children with "special needs" as determined after evaluation may be entitled to educational services between the ages of 3 and 21. A "special needs" child is one who, because of temporary or permanent handicaps stemming from intellectual, sensory, emotional or physical problems, cerebral dysfunctions, learning disabilities, etc. is unable to function and progress in a regular school program and therefore requires special assistance.

Some children with epilepsy may be classified as having "special needs," either because of the seizures or because of other related or unrelated problems that have implications for their education. Traditionally, children with handicaps have either been denied any public education at all (this was frequently the fate of children with epilepsy in the past) or have been grouped together with children with similar handicaps even though the educational needs may not have been similar. The new legislation tries to remove "labels" from children and to group them according to their educational needs and potentials.

Anyone whose child may have special educational needs for whatever reason should contact his/her local school department and track down the staff person responsible for arranging a CORE evaluation for the child. Anyone with concern for and information about the child can take some part in the evaluation; voluminous regulations developed by the Division of Special Education of the Department of Education govern evaluation procedures, and there is opportunity for redress and re-evaluation.

Children between the ages of 3-4 who have a "substantial disability" (a problem that will necessitate a special program for that child when he reaches school age) should be involved in a pre-kindergarten program.

The Division of Special Education has prepared a list of private schools serving various categories of special needs children; these facilities may be utilized by a local school system when it cannot provide an appropriate program within its own community (phone 727-6440).

It is interesting to note that a federal law similar in its provisions to Massachusetts's Chapter 766 was enacted in late 1975 (see section B.2. below).

A useful resource "center for parents and parent organizations to work together to better serve children with special needs and their families" is the Federation for Children with Special Needs, Suite 338, 120 Boylston St., Boston, MA 02116; 617-482-2915. Numerous organizations concerned with different kinds of childrens' problems are members of this federation. Another useful resource is the Massachusetts Advocacy Center, an independent non-profit organization whose purpose is to monitor state human services agencies to see how well they are carrying out their mandated responsibilities; it studies and directs attention to the unmet needs of Massachusetts citizens, particularly children (2 Park Sq., Boston, MA 02116; 617-357-8431).

B. Federal Laws Pertaining to People with Epilepsy

1. Rehabilitation Act of 1973

This major national act, plus the regulations set forth by the Department of Health, Education and Welfare, is the legal basis for providing grants to the states for vocational rehabilitation services (the designated state agency in Massachusetts is the Mass. Rehabilitation Commission). The act mandates that priority be given to services for the severely disabled, and contains provisions (Sections 501, 503, 504) calling for affirmative action programs to reduce discrimination against the handicapped in the federal government and in all private businesses and companies receiving federal contracts and grants.

Section 503 forbids job discrimination in the performance of federal contracts by corporations and other groups who do in excess of $2,500 worth of business with the federal government in any one year. That includes a great many US corporations, including aerospace contractors, the defense industry, the automobile companies, universities, hospitals, and many, many others. There are also requirements for affirmative action plans on the part of these federal contractors detailing future intentions to employ handicapped people.

("Call for Compliance," a hotline offered by Mainstream, Inc., a non-profit corporation, is a new telephone service designed to answer questions about Section 503 from workers and employers. The lines are manned by Department of Labor experts: 202-833-1139.)

Section 504 of the Rehabilitation Act forbids discrimination in employment on the basis of handicap* against otherwise qualified individuals by officers of any program or activity receiving federal financial assistance, and also requires such programs and activities to draw up affirmative action plans for employment of the handicapped. According to the Act's amendments of the 1974, enforcement of Section 504 rests with HEW, which was called upon to establish a coordinating mechanism with the Dept. of Labor. The latter is responsible for enforcing compliance with Section 503.

The anti-discrimination provisions apply, therefore, to large segments of the American economy. Persons experiencing discrimination because of their handicap* should contact Tom Daley of the Mass. Dept. of Labor and Industries (617-727-3567), who will put them in touch with the appropriate federal official to handle the case.

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* "...the coverage of Sections 503 and 504 extends to persons who have recovered--in whole or in part--from a handicapping condition, such as a mental or neurological illness, but who may nevertheless be discriminated against on the basis of prior medical history..." (Excerpt from the report of the Committee on Labor and Public Welfare on the Rehabilitation Act amendments of 1974. The Committee's inclusion of neurological illness and partial recovery clearly covers an individual whose epilepsy is under complete or partial control with medication. Epilepsy is also specifically listed in the 1973 Act as a severely disabling condition and as such is among those to be given priority in vocational rehabilitation programs.)

3. Education for All Handicapped Children Act of 1975 (P.L. 94-142)

This national law, very similar in many respects to Massachusetts's Chapter 766, proclaims the right of every handicapped child to receive an education appropriate to his or her needs. It requires that the designated state educational agency provide full education at public expense for every handicapped child aged 3-18 by October 1, 1978. It calls for an individual educational plan for each child and assurances that structures are established to enforce this.

3. Title XX of the Social Security Act

This 1974 amendment to the Social Security Act provides for joint federal and state payment of expenditures made by the states in providing social services to low incomes persons who are in need. The term "social services" is broadly defined and includes transportation, training, information/referral, protective supervision of children and adults, health education, counseling, adult day care, and many more. In Massachusetts, the Department of Public Welfare is responsible for the administration of Title XX services. Recipients of SSI are automatically eligible for services offered under this title.

4. Developmental Disabilities Services and Facilities Construction Act of 1971 (P.L. 91-517)

Better known as DDSA or the DD Act, this legislation, sponsored mainly by Senator Edward M. Kennedy of Massachusetts and Representative Paul Rogers of Florida, provides funds to serve those who have "neurological handicaps originating in childhood," specifically including mental retardation, epilepsy, cerebral palsy, and (by recent addition) autism and severe learning disabilities. Under DDSA, the federal government grants funds to states on the basis of population, need for services and the financial needs of the state. To date, very little of the total money alotted has been earmarked for alleviating the problems of epilepsy.

5. Military Service

The physical standards for enlistment, induction, or appointment for candidates without previous service, are uniform for all military services in the United States. Department of Defense policy states that regulations concerning physical standards for joining any branch of service will be those set forth in the Army Regulation 40-501. As a general rule, candidates with a history of seizure disorders are considered sub-standard risk in terms of expected military performance; AR 40-501 states in part:

> Paroxysmal convulsive disorders, disturbances of consciousness, all forms of psychomotor or temporal lobe epilepsy or history thereof except for seizures associated with toxic states or fever during childhood up to the age of five are cause for rejection for appointment, enlistment and induction.

There are certain exceptions, such as individuals whose skills are urgently needed. The candidate who does not divulge a history is generally subject to a disqualifying discharge without benefits. Seizures that develop during service after an original four-month period are considered on a individual basis and regarded as "service-connected" and usually qualifies the serviceman for V.A. benefits following service.

ATTACHMENT A

A.

What is Epilepsy?

Epilepsy is a symptom of a disorder of the central nervous system. It is characterized by sudden seizures due to abnormal electrical discharges of brain cells. Because these symptoms are varied and complex, they are more correctly termed "the epilepsies."

Seizures take many different forms, depending on the nature of the electrical discharge. They range from short lapses of consciousness or minor twitching movements to blackouts and violent shaking of the entire body accompanied by irregular breathing and drooling. Isolated instances of seizures do not necessarily mean that a person has epilepsy. The term epilepsy is usually applied only to seizures which occur repeatedly. There are three common forms of seizures:

1) grand mal. Occurs at any age. Takes the form of blackouts and convulsions of the entire body. Some people experience a warning ("aura"), such as unexplained fear, unpleasant odors, odd sounds. After a seizure, a person may feel confused or tired, and may fall asleep. (See Appendix C for instructions regarding assisting a person with a grand mal seizure.)
2) petit mal. Occurs most often in childhood. Appears to be a staring spell and can be mistaken for daydreaming. Other signs may include rapid blinking of the eyes or small twitching movements. Seizures may strike as often as 100 times a day, lasting only several seconds. After the seizure, the person resumes activity as if nothing happened; he or she is frequently unaware of the seizure.
3) psychomotor. May occur at any age but most commonly in adulthood. May take a variety of forms, such as chewing or lip-smacking or other purposeless and inappropriate movements; buzzing or ringing in the ears, dizziness, strong emotions such as unexplained fear or anger; unusual perceptions. Most times the person cannot remember what happened during an attack, and may be confused before and afterward.

There are many causes of epilepsy, but for a large number of cases the cause is unknown. Chemical and physiological conditions are known to be linked to epilepsy. Some of these are: complications in pregnancy, difficulties with childbirth or injuries incurred at birth; severe head injury after birth such as damage caused by an auto accident, certain infectious diseases, or problems with metabolism and poor circulation of blood to the brain. Most epilepsy is not hereditary, though an hereditary predisposition is a factor in some cases.

Drug therapy is the most common method of dealing with the epilepsies. Through the use of proper medication, well over 50% of people with epilepsy can achieve complete control of their seizures to lead full, active lives; another estimated 30% can achieve significant reduction in seizures. Some drugs are more effective in controlling certain types of seizures; nearly half of all epilepsy patients require two or more anti-convulsant medications for effective control of their seizures. Surgery can be performed in a very small number of cases where a lesion (an injured area in the brain) can be removed without impairing brain functions. Emotional adjustment is an important treatment factor. Fatigue, stress and other factors may increase a person's tendency toward seizures and thus decrease the effects of medication.

These lay definitions may assist in understanding some of the terminology used in describing seizures:

akinetic seizure: A type of seizure characterized by a sudden falling forward. There are no jerking movements during its brief duration. Also called "drop seizure."

aura: A subjective sensation that precedes a grand mal seizure in approximately half of all those persons subject to grand mal seizures. The aura is actually the beginning of the attack.

clonic movement: Rhythmic jerking of the body or an extremity.

convulsion (spell, fit, or seizure): A loss or alteration of conciousness accompanied by rhythmic, repetitive jerking.

epilepsy: recurrent seizures.

grand mal seizure: A generalized convulsion characterized by loss of consciousness and stiffening, followed by jerking movements.

idiopathic epilepsy: Recurrent seizures of unknown cause.

infantile myoclonic seizure (infantile spasm, lightning major, jacknife epilepsy): A seizure characterized by a very sudden dropping of the head and flexion of the arms.

minor seizure: A short loss of consciousness, sometimes associated with sudden movement of the arms and legs.

myoclonic seizure (myoclonic jerks): A short loss of consciousness, associated with sudden flexion of the limbs and head.

organic epilepsy: Recurrent seizures whose cause is known.

petit mal: A loss of consciousness lasting less than 30 seconds, without major motor involvement, accompanied by a characteristic electroencephalographic pattern.

psychomotor seizure: A seizure characterized by purposeful but inappropriate motor acts and/or mental events. Sometimes also referred to as "temporal lobe epilepsy," the temporal lobe of the brain being the location of most of these kinds of seizures.

reflex seizure: A seizure precipitated by various types of stimulation, such as touch, pain, smell, or flashing lights.

self-induced seizure: A seizure of any type brought on deliberately by a person who has a convulsive tendency.

status epilepticus: A potentially dangerous condition of unending or frequently recurring seizures, usually of the grand mal type. Rare.

tonic movement: Stiffening or rigidity of the body or an extremity.

Answers to Questions Most Frequently Asked about Epilepsy

Q. Can Epilepsy be completely cured?

A. Often, patients receiving proper amounts of the right kind of medication may go for long periods of time without having seizures. Some have no seizures for six years or more while others may go for one of two years at a time without any sign of recurrence of the seizure or epileptic attack. These same people have histories that might go back to childhood when they had small spells or infrequent spells so that for periods of time they did not take any medication.

The fact that a person has had recurrent seizures in the past makes him liable to have more seizures from time to time. The point at which a person has a seizure is called "threshhold." When young, the threshold is low and seizures are easily brought on by various triggers. With advancing age, the threshold seems to be higher and it is more difficult for a seizure to be brought on. There will be times when the need for medication is greater than at other times, such as teething, puberty, illness, fever.

Therefore, epilepsy is controlled by medication. The prevention of the recurrence of seizures depends upon the dosage and type of medicine required as well as the particular threshold of the individual patient. The type of seizure may determine the threshold. Idiopathic seizures may have a higher threshold than seizures related to brain injury. The tendency to have seizures is always present once the person has shown that they will have them.

It is usually necessary for individuals who require medication to prevent seizures to take this form of preventive treatment indefinitely. Only when a single seizure (not recurrent convulsions or spells) occurs and can be explained by the particular circumstances, such as low blood sugar, alcohol, infection, or other medical cause will the seizure be less likely to recur. In this instance we refer to the seizure as a symptomatic seizure. If it is recurrent without apparent cause, the condition is epilepsy. In that instance, epilepsy is not "cured."

Q. If the medication a person is receiving for epilepsy does not control the seizures, what should be done?

A. The specific medication for a particular patient is determined by the clinical manifestation and appearance of the epileptic attack, the nature of the changes on the electroencephalogram, the response of the patient to medications in the past, the size of the patient to determine the dosage, and the ability of the patient to tolerate certain necessary side effects. It is desirable to obtain the maximum benefit with the minimum amount of side effect from any medication that it used. The neurologist tries to use Dilantin for seizures in which the patient loses consciousness and has generalized shaking (Grand Mal); Phenobarbital is also helpful in these generalized type of seizures. Combinations of Dilantin and Phenobarbital are often used. Mysoline and Mebaral are also effective in major seizures and are similar in chemistry to the Phenobarbital. Phenobarbital is used in children who have minor seizures such as Petit Mal epilepsy, but Zarontin, Celontin, Milontin, and Diamox are often used in Petit Mal. Dilantin may aggravate simple Petit Mal seizures, but may be necessary in those cases where generalized (Grand Mal) seizures are mixed with Petit Mal. Psychomotor seizures are often treated with combinations of Dilantin, Phenobarbital, and Mysoline. Newer drugs that have been tried recently include Tegretol. Research on other new drugs is being conducted in our department. Tridione and Mesantoin have been used in the past. Some people develop side effects to them.

There continues to be a large number of drugs being tried in Europe. After extensive clinical trials under controlled circumstances in Medical Centers, some of these new drugs will become available on the market in the United States. Until the "ideal" drug is found, various adjustments in dosage or types of medications must be made from time to time. Tolerance to certain drugs does develop. Often, it is necessary to change the drug program for a particular patient anticipating increased body size or need. An understanding of the various specific triggers, such as more seizures around menstruation, may require ajustment in medication at that time.

The effectiveness of medication is interfered with by poor habits. Drinking alcohol will usually aggravate seizures regardless of how much medication is being taken. Poor sleeping habits and emotional stress sometimes interfere with seizure control regardless of the amount of medication being taken.

Frequent visits to your physician will improve communications so that an understanding of the dosage to your physician will improve communications so that an understanding of the dosage and types of medications being taken helps the epileptic comply with the program. The most common cause of recurrent seizures in someone who is supposed to be on medication is the irregular taking of the pill or a break - down in the reliabillty of the patient to take what has been properly prescribed.

continued on the next two pages.....

Q. What are the clinical manifestations of epilepsy?

A. The clinical appearance of epilepsy takes many forms. The brain has different functions depending on the particular area involved. One area deals with movements of the arms and legs and face, other areas deal with sensation, other areas deal with speech and hearing, and yet others deal with vision. It has been learned that the irritation of a particular area of the brain during experimental conditions will produce movements or experiences which are controlled by the particular brain cells stimulated.

The spontaneous development of activity within brain cells results in the condition responsible for epileptic symptoms. If the cells that are active are located in a small area then only limited signs would develop. This is known as a **focal** seizure and may be characterized by twitching of one hand or the leg, or the leg and the hand with involvement of the corner of the mouth all on the same side of the body. Consciousness is not disturbed. If the sudden movements of the extremities involve both right and left arms and legs usually consciousness is also lost. This **generalized** seizure may go on for a minute or more with severe stiffening and flexing of the extremities, loss of control of urine or feces, and is followed by a drowsy and confused state lasting as long as 20-30 minutes or more. The words Grand Mal have been attached the type of seizure described. Brief lapses in awareness or consciousness, lasting ten to twenty seconds, without major movement, is known as Petit Mal and is often seen in children. When staring spells are associated with semipurposeful movements of extremities, or automatic behavior, such as repeated hand movements, rubbing, movements of the mouth or swallowing, the seizures are referred to as **Psychomotor.** Memory may be affected during such spells. Other forms of psychomotor seizures may simply involve experiences on the part of the patient, such as having a feeling that something is going on has happened before **(Deja vu)**, unusual smells, a sinking feeling in the pit of the stomach that seems to "swell" up to the neck. On occasion, they develop into a more generalized type spell.

The most important observation that can be made about the clinical manifestation of seizures is the nature of the onset of the observed signs and symptoms. They occur somewhat abruptly and are rapid in their development although they may persist for a variable length of time and recover gradually. Minor spells, such as Petit Mal have sudden onset as well as sudden recovery. To make a distinction between epileptic seizures which are manifested by changes in behavior and disturbances of behavior that are caused by psychiatric problems is often difficult. Hysteria, a form of emotional illness in which the patient has physical symptoms may look like epilepsy when the symptoms take the form of a "seizure." The circumstances surrounding the clinical seizure will help determine whether the seizure is due to epilepsy or hysteria. An electroencephalogram may be helpful in this instance, as well.

Q. Is epilepsy hereditary?

A. Epilepsy is a syndrome. That means that the convulsions or other forms of seizures that are a part of the particular patient's recurrent problem can be caused by various etiologies. Most forms of epilepsy are not hereditary. They may be due to injury (traumatic) or they may be caused by some primary condition of the central nervous system such as infections, or lack of oxygen but in most instances it is idiopathic. Idiopathic seizures do not have an obvious explanation. If seizures are recurrent and do not have an underlying cause that deserves attention such as brain tumor, abcess, or blood clot, the only treatment necessary is medication for control of the recurrence of spells. In this group there may be as many as 20-30% of individuals who pass along the tendency to have seizures.

The tendency to have seizures would simply suggest a lower threshold for spontaneous electrical discharges or epileptic discharges in the brain. This means that a person might have seizures triggered more easily under certain circumstances than another person who has a higher threshold. The lowered threshold might be hereditary. Such individuals, however, may go through life without ever experiencing a seizure even though other members of their family have had them.

Children with seizures associated with high fever may have histories in their families of other individuals who had seizures only when fever was elevated. Quite often, these persons never have seizures under other circumstances and their chances for having them are even further reduced as they get older. It is unlikely that a person who has no family history for epilepsy will pass this tendency on to their children.

continued on the next page.....

Q. **What is the significance of electroencephalogram in understanding epilepsy?**

A. The electroencephalogram is a sample of the activity of the brain as represented by electrical discharges. The recording of this brain wave activity from the surface of the skull, through the bone and skin, requires very sophisticated equipment and well trained technicians. The interpretation of the tracing is done by a person who should have excellent training in electroencephalography and clinical neurology. The correlation of the tracing to the clinical symptoms gives significance to whatever the record shows.

The sample of tracing taken during a period of 20-40 minutes may reflect states of wakefulness and sleeping as well as the symmetrical appearance of all brain waves. A sudden burst of irregularity or sharp activity appearing on one side of the head or other, suggests an epileptic discharge. The characteristics are dependent upon place in the brain where the abnormal discharging or electrical activity originates. Likewise, the clinical symptoms that one observes depends upon the particular location within the brain where a scar or disturbance of brain cells is located. Sometimes, the electrical activity or electroencephalogram from the surface of the brain fails to show disturbances which originate in locations of the brain which are deep and far from the surface of the skull. Under those conditions, an electroencephalogram in a patient with a history of convulsions or temporal lobe epilepsy or other type of seizure might have a "normal" record. Sometimes having the patient stay up all night to produce sleep deprivation brings out more irregularities in the electroencephalogram, accentuating possible seizure activity in the tracing; overbreathing or hyperventilation will accentuate the electroencephalograph changes of epilepsy; photic stimulation is also used to provoke EEG changes under these conditions when a diagnosis is being ascertained. Certainly, improvement in the basic electroencephalogram might occur in a person who had a head injury years ago and has serial tracings over many years. The electroencephalogram improves in its organization with age. A child's record of abnormality consistent with epilepsy might reach a point of "normal" with adulthood.

As long as the clinical seizures occur, the electroencephalogram is not taken as a criterion for treatment. A positive electroencephalogram or "abnormal" tracing is more useful in the confirmation of a diagnosis of epilepsy than is a "normal" one sure evidence to rule it out. Therefore, repeated tracings must be obtained to be certain. The electroencephalogram itself is only a test and one indication for confirmation of the diagnosis, but an essential one.

Q. **What are some of the side effects of the medicines used for epilepsy?**

A. Researchers have looked for the "ideal" anticonvulsant for many years. Such a drug would have no side effects and be able to prevent the recurrence of seizures in epileptic patients when taken on a regular basis. However, the drugs commonly used have side effects. Phenobarbital causes drowsiness as does Mysoline. Dilantin may cause a rash and in higher doses produce unsteadiness of walking, slurred speech, and blurred vision. Celontin, Zarontin, and Milontin sometimes cause irritability and even personality changes. Drowsiness may also be a side effect of these medications. Tridione, Paradione and Tegretol often cause changes in the blood count. Clotting capabilities is affected with Tegretol in some individuals. As with any medication, side effects and toxic effects must be watched for. The clinical manifestations of toxicity (overdose) are similar to the side effects cited here and may be confirmed by blood level determinations.

These are some questions that are commonly asked on radio and t.v. talk shows and in letters. They have been answered here by Dr. Robert Feldman, chairman of the Department of Neurology at B.U's University Hospital and Chairman of Board of Advisors of the Epilepsy Society of Massachusetts.

If you have more questions please send them to Dr. Robert Feldman, c/o the Epilepsy Society of Massachusetts, 3 Arlington St., Boston, Mass. 02116.

ATTACHMENT C

"First Aid" -- What To Do When A Major Seizure Occurs

1. Keep calm. You cannot stop a seizure once it has started. Ordinarily the attack will be over in a few minutes, whatever you do or don't do.

   Remember these points: The person is not going to die and is not in pain, no matter how agonizing the seizure may look. The person does not need a doctor, unless--and this doesn't happen often--he passes from one seizure to another without gaining consciousness or his seizure lasts beyond 8-10 minutes.* The condition is not catching and will not normally damage the person's brain.

2. Try to make sure the person doesn't hurt himself by knocking against something; remove hard, sharp, or hot objects from the area. Loosen tight clothing. Do not restrain the person or interfere with his movements, except as may be necessary to prevent skull or spine fracture or other serious injury. Place a pillow or rolled-up coat under the head, if possible.

3. Do not force anything between the teeth. The person will not swallow his tongue. It is usually best for laypersons to avoid the temptation to put something hard in the mouth--the danger of injuring teeth or gums is greater than the benefit of preventing the person's biting his tongue. If an object is inserted, it must be firm but not too hard, nor subject to splintering or breaking, nor obstructive. Never force open clenched jaws.

4. Don't be concerned is the person seems to stop breathing or becomes blue-ish temporarily. Do be concerned in the rare event that the person passes from one seizure to another without regaining consciousness--seek emergency medical assistance. The major threat to life in an on-going seizure is vomiting and aspiration; in these instances and as the convulsive movements subside, turn the person on his side and make sure the air passage is clear.

5. Once the convulsive movements stop, you may turn the person on his side to assist his tongue to fall forward and excess saliva to drain out of the mouth. Let him rest afterwards if he wants to: there may be a period of physical exhaustion and/or mental confusion following a major attack. Smile, relax, and treat the person normally, without fuss or bother.

There are few ways to help a person after a major seizure: make sure he is not left unattended until he has fully recovered. Urge him to obtain and wear emergency medical identification if he doesn't have any. Urge him to seek prompt medical attention if this was his first seizure or if he is not under treatment for the condition. Offer a full description of the seizure, as this information may be useful to the person and to his physician.

The above points apply to "grand mal" (convulsive, or major motor) seizures; petit mal seizures require no special steps. The best way to handle most psychomotor seizures is to let the person continue his activity without restraint.

* status epilepticus

ATTACHMENT D

Emergency Medical Identification

People who cannot speak for themselves because of a medical problem benefit from carrying or preferably wearing emergency medical identification which makes it clear to passers-by, police, firemen, paramedics, emergency room teams, etc. the the nature of the condition.

Such identification has several uses:

--It will often prevent expensive and time-consuming hospitalization and diagnostic testing.

--It may reduce the danger of misunderstanding the source of mental confusion or behavioral abnormalities which may precede, accompany or follow a seizure. Such confusion can be wrongly attributed to the use of alcohol or drugs or to mental illness.

--The rare but potentially harmful (to the person himself) condition of "status epilepticus," in which seizures follow rapidly one after another or are prolonged, can be more effectively and quickly treated.

There are various sources of medical identification. Widely recognized is the Medic Alert emblem, worn on the wrist or on the neck. The cost is $7.00 for a bracelet, and the service includes a toll-free number which gives important background information on the patient. The fee can be waived in hardship cases, and is reimbursable by Medicaid in Massachusetts (the physician must order the device, pay for it and then bill the state). Application forms are available through the Epilepsy Society of Massachusetts (617-267-4341). For large quantities and information about Medic Alert, contact Boston Life Underwriters (200 Berkeley Street, Boston; 542-0324), which distributes Medic Alert locally as a public service project. Locally, medical identification cards are available from Security Photo (1104 Commonwealth Av., Boston 02215; 232-8080).

A new device, the Emergency Medical Instructor (EMI), is on the market and should prove very helpful to some persons with sudden-onset, hard-to-manage seizures. The EMI automatically broadcasts a personalized pre-recorded 4-minute message of information and specific medical aid instructions if its wearer suddenly becomes unconscious. The EMI costs $200; for information contact Emergency Medical Systems Corporation, 1104 Commonwealth Av., Boston, MA 02215; 232-3444.

ATTACHMENT E

Some Sources of PERSONAL IDENTIFICATION for Persons
Not Eligible for a Driver's License

1. A passport is an excellent means of identification. Consult the Passport Agency of the United States Dept. of State: JFK Federal Building, Government Center, Boston, MA; 617-223-3831.

2. Many of the larger banks and supermarket chains have their own identification cards or other mechanisms for identifying their own customers. Such cards have limited use, but can be very helpful in getting a check cashed at a branch or cooperating bank or store. A few banks issue their Master Charge card with a photo.

3. Most ID cards obtainable from drugstores or photo studios are not generally accepted for check-cashing purposes. The following company provides a valid photo identification card requiring proof which is generally accepted:

Security Photo
1104 Commonwealth Av.
Boston, MA 02215
617-232-8080

Their ID cards costs $7.50 plus tax. Four proofs of identification are required, including a birth certificate and a social security card; another identification with a photo is desirable. The card can be issued on the spot without appointment.

Note: Massachusetts, along with approximately half of all the states in the country, does now offer any official state-issued identification document other than the driver's license which is suitable for general identication and check-cashing purposes. ~~However, a bill has been filed for consideration~~ by the 1977 Legislature "providing for an identification card for handicapped persons for certain purposes." This bill or others with similar intent are worthy of support from people who are not eligible for drivers' licenses. *** A liquor identification card is available from local licensing authorities but is not ~~suitable~~ for other use.

contact local registry of motor vehicles office

ATTACHMENT F

A few Words about INSURANCE for People with Epilepsy

Life insurance and health insurance may be difficult, expensive, and in some cases impossible for people with epilepsy (and a number of other health problems) to obtain. Whenever possible, a person with epilepsy is well advised to enroll in a group life or group health insurance plan available through his place of employment; group plans are the least expensive and coverage usually is automatic without regard to the individual's state of health. If group coverage is not possible, individual policies can be considered. Many factors influence the underwriting of both individual life and individual health insurance policies, and it would be impossible to give appropriate consideration to all of them here.* It is definitely recommended that the prospective buyer "shop around." According to Mr. Wilbur Bullen of Underwriters Service Agency, Inc. of Boston, an agency which represents companies which specialize in writing sub-standard life insurance, a variety of life insurance plans are now available to people with epilepsy. Some companies will underwrite people whose epilepsy is controlled at standard rates for both term and whole life; some policies are available even for those with incomplete control--many factors are involved, but no person should conclude that he is completely uninsurable until he has thoroughly explored the possibilities. (Contact Mr. Bullen at Underwriters Service Agency Insurance, Inc., 89 State St., Boston; 523-6820).

Health insurance is also available in many different forms. Membership in a health maintenance organization, through either a group plan or an individual policy, is desirable for people with on-going medical expenses. Health policies will often exclude a pre-existing condition such as epilepsy or diabetes or will charge higher rates to the individual with the condition. Again, shop around. For information on insurance carriers, contact the Epilepsy Society of Massachusetts (267-4341 -- e.g. a group life policy is available to some members of the Epilepsy Foundation of America).

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* An exhaustive presentation of all kinds of insurance and their relation to the person with epilepsy is the Insurance Handbook for Persons with Epilepsy (R. Eilers and J. Malone, Epilepsy Foundation monograph), available for perusal at Epilepsy Program, Mass. Dept. of Public Health.

(Insurance -- continued)

Fortunately for people with epilepsy in Massachusetts, there are no special requirements or rates charged to persons with health conditions for automobile insurance in this state. Insurance comapnies may ask questions about medical disabilities on their application forms, but rates are in no way affected by the presence of a health problem. State law specifically prohibits insurance companies from requiring a medical examination prior to issuance of auto insurance (Chapter 175, Section 113N) (1972); the only permissabl grounds for refusing insurance are non-payment of premiums and lack of a driver's license. If, therefore, a person with epilepsy has validly obtained a license from the Registry of Motor Vehicles (q.v.), he should have no problems or higher rates in obtaining auto insurance. (Rates depend on where the vehicle is garaged, type of use, etc.; a new rating plan also gives consideration to the past accident, violation and loss record as well. Now that rates have become competitive in Massachusetts, a buyer is again well advised to shop around. If an applicant encounters difficulties, he should contact the legal staff of the state's Insurance Division (617-727-3364).

ATTACHMENT G

Saving Money on Drug Costs

People who want to save money on their drug expenses can consider these options.

1) Shop around. Massachusetts has a number of discount pharmacies that offer many standard drugs at prices below those charged by neighborhood pharmacies. A telephone survey conducted by the Epilepsy Society of Massachusetts revealed that large pharmaceutical chains such as (among others) Osco, Medi-Mart and CVS tend to charge lower prices. Hospital pharmacies are often cheaper than regular pharmacies, but you need a prescription from a hospital physician to use them. Another approach is to develop a personal relationship with a local pharmacy, and request a discount on the grounds that you are a regular, long-term local customer.

2) Check out your own health insurance plan, if you have one--it may reimburse you for a percentage of your drug expenses. Many insurance companies provide partial payment for medicines under their over-all individual and group health policies. Each company and each policy differs in its formula of payment but basically this is how it works: There is a fixed deductible amount that ranges from $25-100 and this must be paid first by the policyholder to his druggist. (In many policies, this applies to all the medical costs, i.e. doctor, hospital, medicines, etc.) After the amount of the deductible is subtracted or used up, the cost of the medicine is reimbursed to the policyholder at a percentage rate of the actual amount paid. Confusing though they are, the deductibles and percentage payments are well worth looking into. Consider this typical case. If your policy provision is the full medical type with $100 per year deductible and 80% reimbursement, and you spent $500 on all your drugs over the past year, you would pay the $500 out-of-pocket and receive back $320 from your policy claim. Read carefully the reimbursement provisions of your policy, then call your insurance company office and find out how to make application for reimbursements.

3) Consider joining the Epilepsy Foundation for $12 a year; such membership entitles one to purchase all drugs for all members of the family at discount prices, via mail, from Pastor's Pharmacy in Pennsylvania. EFA membership confers other benefits and includes membership in its affiliate the Epilepsy Society of Massachusetts; for further information phone ESM at 617-267-4341.

4) Consider purchasing epilepsy drugs through the National Epilepsy League Pharmacy Service at discount prices, via mail; membership in this service is $1/year. Write for information and a price list to: N.E.L. Pharmacy Service, 116 South Michigan Av., Chicago, Ill. 60603.

5) State assistance. The Department of Public Welfare covers drug expenses for people on Medicaid, and anti-convulsants are covered as "life-sustaining" drugs for people on General Relief. The Dept. of Public Health covers 100% of anti-convulsant drug costs for eligible individuals through direct payment to the pharmacist (phone 617-727-5822).

6) Ask your physician about prescribing a generic rather than a brand-name drug. This must be the physician's decision, but they are generally quite a bit less expensive.

ATTACHMENT H

H.

Clinical Pediatric Neurology Services
funded by or offered through
the
Massachusetts Department of Public Health

The Department of Public Health provides or funds certain neurological services for children and teenagers (ages 0-21) who have or are suspected of having epilepsy Under these programs, one diagnostic visit is available without charge to any family, after registration; families of patients accepted for continuing care and financial assistance may be asked to contribute to costs of treatment, depending on ability to pay. There are basically two categories of programs: the first, a bill-paying arrangement with several Boston hospitals, and the second, a series of community-based DPH clinics located throughout the state.

1. Greater Boston area - "Handicapped Children's Seizure Program"

Several major hospitals serving the greater Boston area cooperate with the Department's Epilepsy and Services for Handicapped Children's programs. These programs are designed to offer financial assistance to families who need help with the costs of medical care for a child with epilepsy. Under these arrangements, services are provided by the cooperating hospital and the bills are paid, in whole or in part, by DPH. After appropriate registration (see list of cooperating clinics below), one diagnostic visit is paid for by DPH for any Massachusetts family whose child or teenager (aged 0-21) has or is suspected of having epilepsy. Near the time of the initial visit, a family interested in further financial assistance will be asked to fill out an application form and a financial information sheet, which will be forwarded by the hospital to DPH. For eligible families, the Handicapped Children's Seizure Program covers the costs of out-patient neurology or seizure clinic visits, anti-convulsant medications, and, in some instances, emergency treatment related to seizures and other treatments resulting directly from the child's epilepsy. A family with health insurance may apply to the Seizure Program, as sometimes there are expenses not covered by insurance which can prove burdensome. For detailed information about the programs and for specifics about coverage, contact Mr. Edward Lichtenstein, Director of DPH's Epilepsy Program (357-5002, x. 60).

Application Procedure: A family should make an appointment with the desired hospital clinic (see list below) through normal channels. They should then specifically request information about the program and an application for the Handicapped Children's Seizure Program from the contact person listed below:

Children's Hospital Medical Center: Seizure and Neurology Clinics
300 Longwood Av.
Boston, MA 02115
Contact: Ms. Ellen Fishman, Social Worker, Seizure Unit
734-6000, x. 2591

Tufts-New England Medical Center: Pediatric Neurology & Seizure Clinics
171 Harrison Av.
Boston, MA 02111
Contact: Ms. Sheila Riordan, Community Services Coordinator
956-6038

Massachusetts General Hospital: Pediatric Neurology Clinic
Fruit Street
Boston, MA 02114
At the initial visit, request a referral to the Handicapped Children's program through Mr. Philip Lenz or Mrs. Ruth Lewis, Clinics Admitting Office; 726-2700

H (continued)

The Epilepsy Program also makes available to this hospital funds for the diagnosis and treatment of epilepsy, when financial need exists:

Joseph P. Kennedy, Jr. Memorial Hospital
30 Warren Street
Brighton, MA 02135
Contact: Ms. Jill Ginsburg, Neurology Department
254-3800, x. 284

2. Outside Greater Boston - Pediatric Neurology Clinics run by the Department of Public Health

Pediatric neurology clinics have been established by the Epilepsy Program in collaboration with the Department's program of Services to Handicapped Children (SHC), to provide specialized diagnostic services, medical treatment and social services for children with neurological conditions, including epilepsy.

Eligibility and Charges: Diagnostic services, including hospitalization when necessary, are available to any Massachusetts resident under 21 who is suspected of having epilepsy or any other neurological condition.* On-going care is provided to patients in the community-based clinics based on the diagnosis; charges, if any, depend on the financial situation of the family. No charge is made for the diagnosis or for physicians' or staff services; in some cases, depending on the ability of the family to pay, charges may be made for other services purchased (e.g., appliances, medications). The financial liability of the family is assessed individually and personally by the clinic social worker and reflects the size of the family, net income, and the extent of family medical expenses.

Services: Medical care is provided by a team, including a pediatric neurologist, clinic nurse and social worker. Hospitalization is provided when necessary for diagnostic work-up or emergency care. Third party payment for services is utilized wherever possible. Financial assistance is available to families with limited means for diagnostic tests, EEG's, x-rays, laboratory procedures, and anti-convulsant medications. In an effort to insure comprehensive care, referrals are made to other agencies for vocational rehabilitation, mental health counseling, special education, long-term care and other services not provided directly by the Department of Public Health. Free genetic counseling is available on request.

Referral and Application: Children and teenagers may be referred by private physicians, hospitals, community service agencies, schools, parents or other individuals.* Applications should be requested from the neurology clinic social worker at the regional health office serving the most convenient clinic (list on next page). For services in Greater Boston, please refer to the Handicapped Children's Seizure Program available through several major hospitals in Boston.

* In cases of suspected learning disabilities or mental retardation, the neurology clinics accept referrals from schools or parents only if a physician believes there is reason to suspect neurological involvement.

The Commonwealth of Massachusetts
Department of Public Health
EPILEPSY PROGRAM
39 Boylston Street, Boston 02116
617-727-5822

JONATHAN E. FIELDING, M.D.
COMMISSIONER

PEDIATRIC NEUROLOGY CLINICS

Area Served and Clinic Location	For Information and Application, Contact the Clinic Social Worker at the administering Regional Public Health Office
Western Massachusetts Pittsfield Neurology Clinic Berkshire Medical Center Pittsfield	Western District Public Health Office 246 North Street Pittsfield, MA 01201 413-443-4475
Springfield Neuro Clinic - Bay State Medical Center	
Central Massachusetts Southbridge Neurology Clinic Harrington Memorial Hospital Southbridge	Central District Public Health Office Rutland Heights State Hospital Rutland, MA 01543 617-886-~~6111~~
Worcester ~~Webster~~ Neurology Clinic U. Mass ~~Hubbard~~ Regional Hospital ~~Webster~~ Worcester	4711 X.136
Northeastern Massachusetts Tewksbury Neurology Clinic Tewksbury State Hospital Tewksbury	Northeast Regional Public Health Office Tewksbury State Hospital Tewksbury, MA 01876 617-851-7261
Southeastern Massachusetts Lakeville Neurology Clinic Lakeville State Hospital Lakeville	Southeast Regional Public Health Office Lakeville State Hospital Lakeville, MA 02346 617-947-1231 (ask for Handicapped Children's Services)
Cape Cod Cape Cod Neurology Clinic Barnstable County Hospital Pocasset	Barnstable County Health Department Barnstable County Courthouse Main Street Barnstable, MA 02360 617-362-2511, ext. 331

These neurology clinics are administered by the program of Services to Handicapped Children in collaboration with the Epilepsy Program of the Massachusetts Dept. of Public Health. Services are available at little or no charge to Massachusetts residents under 21, following appropriate application and registration.

For information about services in greater Boston, contact the Epilepsy Program at 617-727-5822. The Department of Public Health funds out-patient services for children with epilepsy at certain cooperating hospitals in the Boston area; the Epilepsy Program will refer to the contact person at the preferred hospital, who will assist in the application process.

DPH

ATTACHMENT I Recent Developments in the Treatment of Epilepsy

Gas-Liquid Chromatography (GLC) - Method of analyzing blood samples so that the amount of anti-convulsant present in the blood can be determined. Blood is the substance which conveys anticonvulsant chemicals to the brain; therefore, if the level is low it means that the drug is not reaching the sources of the seizures in sufficient amounts to prevent their occurrence. On the other hand, too much anticonvulsant can cause serious side effects, and the GLC tests will warn the physician when levels approach this point. The process is considered to be a major aid to physicians in maintaining maximum seizure control in their patients. In late 1976 the Epilepsy Foundation of America received a federal grant to establish and monitor basic standards for gas-liquid chromatographic studies.

Computerized Axial Tomography (CAT or CT or EMI scan) - A device that can take cross sectional x-ray pictures of the brain and, through the use of a computer, produce enhanced images of underlying brain structure. So detailed are the pictures that a series of them displayed on a screen may show physicians the precise location and form of abnormalities in the brain. An advantage of the CAT scan process is that it does not require placement of dyes or other substances in the brain (however, many scans are now performed with an injection of intravenous contrast material for greater clarity in reading); it is completely painless and can be performed on an out-patient basis. Since epilepsy is, by definition, the outward symptom of an underlying malfunction or lesion within the brain, the new technique is expected to improve diagnosis, and to yield new knowledge of the relationship between brain structures and seizures.

Enzyme Multiple Immunoassay Technique EMIT) - A new method of analyzing the level of anticonvulsants in the blood. This system has been undergoing extensive evaluation at Presbyterian Hospital in New York and other major medical centers. The advantages of the new system include the speed with which results can be produced (in minutes) and the fact that up to five assays can be run on one very small sample. The EMIT system can now test for phenobarbital, phenytoin, and primidone; others will be added in the near future. Another advantage is that the blood level reading can be performed on infants and even newborns, whereas the relatively large blood sample required for GLC testing makes that procedure impractical for small children.

Behavior Modification (Behavioral Medicine) - An assortment of procedures designed to teach the patient self-control, desensitization of trigger and anxiety-producing situations, and the ability to discriminate seizure risk events and to behave so as to avoid, eliminate, or attenuate the consequences. Most of the techniques are familiar to existing programs where educational or emotional habilitation is carried out. The specific procedure selected by the therapist will depend on many factors: age and status of the patient, nature of the seizure disorder, whether treated as an outpatient or in a ward setting, availability of personnel and facilities. In general, the essential characteristics of most of these programs (which may include biofeedback, see below) are: maintaining an accurate log, monitoring of the environment, and appropriate reward and non-reward contingencies. The recognition that behavioral control techniques may be applied to seizure disorders is relatively new. It promises to be of substantial value as an adjunctive therapy in epilepsy management, and one which is neither costly nor involves risk.

Biofeedback - A therapy based on the concept that individuals can, through conditioning, develop a degree of control over involuntary physical processes. In animal studies, monkeys have apparently learned to control the firing of individual brain cells. In epilepsy-related studies on human patients, the goal has been to produce a brain pattern identified as the sensori-motor-rhythm (SMR) which may have an inhibiting effect on seizures. The conditioning process involves EEG monitoring of brainwave patterns, with a tone or light displayed when the appropriate brain readings are achieved. Research is presently limited to a few institutions and small numbers of patients.

ATTACHMENT J

A Few Words About Advocacy

Known to man since ancient times, epilepsy remains even today an enigma. Even the majority of cases, which lend themselves to complete medical control of seizures, may present psychological, vocational, and/or financial problems. Many of these problems originate in the attitudes and practices of the society at large. The person with epilepsy may benefit from the assistance of a well-trained advocate in dealing with a too-frequently uninformed or misinformed world. It may help to keep these points in mind:

1) Know the facts. For example, if the issue is what to do about employment discrimination, don't look for laws preventing discrimination against "epileptics" (there are none), but know that people with epilepsy are covered under state and federal statutes referring to "handicapped" persons. (This is true even if the person does not consider himself or look to you to be in any way handicapped.) Or, if the issue is career guidance, don't recommend a future in the armed services.

2) Know your client--and his epilepsy. When someone tells you he has epilepsy, that tells you about a tendency toward abnormal electrical discharges in his brain. It tells you nothing else. Does he or she have seizures? What kind, and when? Do they bother him much or interfere in a big way with functioning? Is he getting the best possible medical attention? Does he take his drugs and follow other medical advice? Is there a disability, related to or unrelated to the epilepsy? What else is going on in his life? What kind of person is he, and what does he need and want out of life and out of your client/advocate relationship? What are his problems? Are they more in his head or in the environment, the world outside? What are his talents? What can you do to bring him to the point where he'll be his own best advocate?

3) Know yourself. What are you attempting to offer him? Can you recognize what you can't handle and "farm it out"? Can you walk the thin rope between personal warmth and professional discretion?

4) Root out the real source of problems that the client attributes to epilepsy. For example, if the person says he can't get a job because he has epilepsy, is the issue simple employer discrimination based on prejudice, or is it lack of preparation or skills, a negative or timid attitude, uncertainty about how or whether to present the issue of epilepsy, old-fashioned bad luck, etc. etc. If it's pure and simple discrimination, you go the education/persuasion route and, that failing, the legal route. If it's a lack of training, your recommend vocational preparation; if personal insecurity, discussion groups and supportive counseling, and so on. Sometimes medications or possibly subliminal seizure activity may cause personality problems--such judgments are difficult and sometimes impossible even for the best-qualified physicians to make. You have to know when not to think we have all the answers.

5) Educate all along the way. You'll find people (including those with epilepsy!) will be surprised to learn the multitude of types of seizures that constitute "the epilepsies," the spectrum of problems that may be caused or complicated by having epilepsy, the fascinating history of attempts to treat the condition and understand its causes, recent developments in medical research...and how they themselves can help.

6) Use the epilepsy agencies and programs. Our staffs will help whenever we can. Brochures and films are available as well as free advice, referrals, consultation (see the beginning of this handbook for our whereabouts).

ATTACHMENT K

Prevalence and Incidence of Epilepsy

(Ed. Note: Much of the information in this summary is gleaned from Basic Statistics on the Epilepsies, prepared by the Epilepsy Foundation of America, 1975.)

Early estimates, based on studies of World War I and World War II applicants, indicated a prevalence rate of 5 per 1,000 population. More modern studies give estimates ranging from 2 to 22[1] per 1,000, with an average of such studies suggesting a prevalence of between 5 and 10 per 1,000.[2] This means one case of epilepsy for every 100-200 people. The variation in the figures is so great because of differences in the definition of epilepsy, methodologies, possible variations according to age, incidence, and sex.[3]

The Professional Advisory Board of the Epilepsy Foundation of America, based on the studies plus the assumption that epilepsy is not infrequently unreported, under-reported, misdiagnosed, or undiagnosed, estimates a prevalence of at least 2% of the present population of the United States, or a minimum of 4 million people. This means 2 cases of epilepsy for every 100 people. The federal government's National Institute of Neurological and Communicative Disorders and Stroke estimates a 1% prevalence, i.e. 2 million Americans, but guesses there may be "millions" more cases of "secret" or undiagnosed epilepsy.

Epilepsy is therefore much more common than most people think.

The annual incidence rate, i.e. the number of new cases that develop over the course of a year, is estimated to be between .1 and .7 per 1,000. This suggests perhaps 70,000-80,000 new cases of epilepsy in the United States each year. With a Massachusetts population of approximately 6 million, we can expect about 1200 new cases of epilepsy to develop over the course of the next 12 months. These cases, individuals of all ages and their families, are particularly in need of prompt, competent, thorough medical and support services.

Age-specific incidence studies from Great Britain report that epilepsy is most likely to develop during the years 0-4 and 10-19. Probably 75% of all cases of epilepsy develop during the first two decades of life. The Epilepsy Foundation of America comments: "Unfortunately, as preventive medicine decreases the incidence of epilepsy due to prenatal and postnatal care and infections, the number of head injuries seems to be increasing due to accidents, especially traffic accidents."[4]

It is frequently impossible to identify those persons with epilepsy who die from other causes, so collecting reliable mortality and longevity data for epilepsy is extremely difficult. It is likely that mortality rates for people with epilepsy are 2-3 times higher than those for the general population (some epilepsy-related deaths are attributable to accidents, to underlying diseases such as brain tumors, to suicides, etc.). The probability of dying from a seizure is not high, however; one is more likely to die from an appendix operation than from epilepsy.

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1 The high figure of 22 per 1,000, unique among studies, included febrile convulsions, most cases of which do not develop into epilepsy.

2 The following data were presented at the Seventh International Symposium on Epilepsy, held in Berlin, Germany, in June 1975: Registration of all patients with epilepsy in a metropolitan area of Denmark (pop. 240,000) since 1964 indicates a prevalence of 6.8 per 1,000; an extensive Polish study revealed that 1/3 of people with epilepsy, particularly adults with psychomotor seizures, had not sought medical attention.

3 Some recent work indicates a slightly higher prevalence in males, but this is controversial.

4 This is a good argument for the use of seatbelts in autos, helmets for motorcyclists, observance of the 55 mph speed limit, and appropriate occupational safety measures.

ATTACHMENT L

L.

Good Books on Epilepsy

(The following bibliography, while not comprehensive, lists books which we have found helpful. Suggestions for additions to this list are welcomed; please send to Epilepsy Program, Mass. Dept. of Public Health.)

For General Audiences

Baird, Henry W.
The Child with Convulsions: A guide for Parents, Teachers, Counselors and Medical Personnel
Grune and Stratton
1972 144 pp.

Lagos, Jorge C.
Seizures, Epilepsy and Your Child
Harper-Row
1974 cost: $7.95

Lennox, William G.
Science and Seizures
Harper-Row
1941, revised 1946
(Though an older work, this book is beautifully written. It is available on loan from the Epilepsy Society of Massachusetts.)

Livingston, Samuel
Living with Epileptic Seizures
C.C. Thomas, Springfield, Ill.
1963 348 pp.

Scott, Donald
About Epilepsy
International University Press. New York
1973 (2nd edition)

Silverstein, Alvin and Silverstein, Virginia B.
Epilepsy
J.B. Lippincott, Phila.
1975 64 pp. available in paperback: $1.95

Temkin, Owsei
The Falling Sickness: A History of Epilepsy from the Greeks to the Beginnings of Modern Neurology
Johns Hopkins, Baltimore
1971 467 pp.

Medical Texts

Boshes, Louis and Gibbsm Frederick A.
Epilepsy Handbook (2nd edition)
C.C. Thomas, Springfield, Ill.
1972 196 pp.

Lennox, William G.
Epilepsy and Related Disorders (2 vol.)
Little Brown, Boston
1960 1168 pp.
(Out of print. Available on loan from E.S.M.)

Livingston, Samuel
Comprehensive Management of Epilepsy in Infancy, Childhood and Adolescense
C.C. Thomas, Springfield, Ill.
1972 667 pp.
(May be perused at Mass. Dept. of Public Health; not available for loan.)

Rodin, Ernst
Prognosis of Patients with Epilepsy
C.C. Thomas, Springfield, Ill.
1968

Topics of Special Interest

Bagley, Christopher
Social Psychology of the Epileptic Child
University of Miami
1971 307 pp.

Barry, Steven T.
The Mid-Career Epileptic: Problems of the Onset of Epilepsy in Adulthood
Epilepsy Society of Massachusetts, Boston
1971 21 pp.
(Available on loan and may be copied; from E.S.M.)

Caveness, William F.
Trends in Public Attitudes Towards Epilepsy in the U.S.: 1949-1974
Merritt, H. Huston and Gallup, George G.
National Institutes of Health, Washington, DC
1969 21 pp. (approx.)

Guerrant, John
Personality in Epilepsy
C.C. Thomas, Springfield, Ill.
1962 112 pp.

Goldin, George J.
Rehabilitation of the Young Epileptic: Dimensions and Dynamics
Lexington Books (D.C. Health and Co.), Lexington, Mass.
1977 130 pp.

Wright, George N. (ed.)
Epilepsy Rehabilitation
Little Brown, Boston
1975 275 pp.
(A comprehensive work of interest to everyone in the field; available for perusal, but not loan, at Mass. Dept. of Public Health.)

Note: Many of these books, even those not so noted, are available on loan from the Epilepsy Society of Massachusetts. Phone ESM at 617-267-4341 to make arrangements for borrowing.

ATTACHMENT M

FILMS AND TEACHING AIDS ON EPILEPSY

All films are 16 mm with sound and, unless otherwise noted, are available on loan without charge from the Epilepsy Society of Massachusetts. Order blank is at the end of the list.

NAME of FILM and DESCRIPTION	Type of Audience: General Audiences	Teachers	Children	Teenagers	Parents	People with Epilepsy	Health Professionals (Gen'l)	Nurses	Emergency Medical	Employment Profs.	Year Produced
BENJAMIN - An animated film about a boy who has epilepsy and his relationships with his classmates and teacher. Aimed at 1st, 2nd, and 3rd grades and fun for everyone. Animated by Carroll Spinney ("Big Bird" and "Oscar" of Sesame Street) and narrated by Susan Long ("Miss Susan" of Sesame Street"). 5 min.			X								1971 color
CHILDREN WITH EPILEPSY - Shows numerous varieties of seizures, including hysterical seizures. Technical discussion of classification and sites of origin within brain.* approx. 30 min.							X	X			1960's color
DARK WAVE - Fine non-medical film starring Hollywood's Charles Bickford and Nancy Davis. Tells story of Debbie, an 11 year old girl with epilepsy, and how the intelligent attitudes of her classmates, teacher and parents keep her from feeling unwanted. 24 min.	X	X			X						1958 color
DOCTORS TALK ABOUT EPILEPSY - Designed primarily for physicians who do not specialize in neurological disorders, the film features eminent medical authorities in epilepsy. Covers differential diagnosis, treatment and new developments. Suitable also for other health professionals. 24 min.							X	X	X		1975 color
EPILEPSY - A Swedish film dubbed and sub-titled in English, depicting a young man who develops epilepsy following a falling accident. It concentrates on personal and work issues, stresses how with a supportive and receptive work environment the person with epilepsy can handle almost any job. 15 min.	X						X			X	1960 B&W
EPILEPSY: DON'T LOOK AWAY - Dispells some of the myths and underlines human and monetary costs. Offers suggestions on how concerned individuals and groups can help alleviate some of the problems associated with epilepsy. 12 min.	X									X	1975 color
EPILEPSY: FOR THOSE WHO HELP - Designed for those who handle seizures in public and in emergency situations. Emphasis is on recognition of symptoms and emergency procedures which minimize injurious side-effects of seizures. 12 min.							X		X		1975 color

* Available only through the Seizure Unit, Children's Hospital Medical Center (617-734-6000, x. 2591).

NAME of FILM and DESCRIPTION	General Audiences	Teachers	Children	Teenagers	Parents	People with Epilepsy	Health Professionals (Cont'd)	Nurses	Emergency Medical	Employment Profs.		
EPILEPSY: FOR THOSE WHO TEACH - Designed to help school staff understand what epilepsy is, how to handle seizures in the classroom, and how to give emotional support and class understanding to the child with epilepsy. 13 min.		X						X			1975	color
EPILEPSY: PASS THE WORD - A practical view of the employment considerations and problems of persons with epilepsy, designed primarily for employment and rehabilitation counselors, employers, personnel managers and unions. 12 min.										X	1975	color
THE EXCEPTIONAL CHILD - Part of a series made for educational TV, this film discusses epilepsy from the parents' and teenagers' viewpoints. Teenagers with epilepsy talk about marriage, driving, employment and general life goals. Issues and feelings are contemporary though the film is dated. 25 min.		X			X		X				1948	B&W
FITTING IN - An introduction to the "developmental disabilities," i.e., epilepsy, mental retardation and cerebral palsy. A case history representing each condition is presented in his or her daily living context. Contemporary.* 25 min.	X				X		X	X			1976	color
GRAND MAL EPILEPSY: DIAGNOSIS AND MANAGEMENT - Depicts the complete medical diagnostic process for teen and adult patients. Tells story of 17 year old girl who develops grand mal; discusses myths surrounding epilepsy; also shows other types of seizures. 23 min.							X	X	X		1968	color
IMAGES OF EPILEPSY - Through a "film within a film" technique, the viewer experiences how it feels for a child or teenager to have one of the major forms of epilepsy (petit mal, psychomotor, grand mal). Seizures are shown, but the emphasis is on the educational and social environment. 18 min.	X	X		X	X						1975	color
I'M THE SAME AS EVERYONE ELSE - Canadian film presenting several teenagers and young adults, including a neurologist, coping with epilepsy in their everyday lives. Contemporary, non-medical and genuine portrayal of personal implications.* 26 min.	X			X	X	X	X	X			1976	color
LIVING APART - Older British film which is still up-to-date as regards information. Consists largely of interviews with ordinary people with epilepsy, who comment frankly and fully on their concerns. Various professionals also discuss their roles. Shows grand mal and petit mal seizures. approx. 30 min.	X				X	X				X	1950 (?)	B&W

* Available only through Mass. Dept. of Public Health Epilepsy Program (day loan only) (617-357-5002, x. 60).

NAME of FILM and DESCRIPTION	General audiences	Teachers	Children	Teenagers	Parents	People with Epilepsy	Health Professionals	Nurses	Emergency Medical	Employment Pro	
MODERN CONCEPTS OF EPILEPSY - Technical professional education film covering causes, differential diagnosis, and treatment. Some attention to personal and social implications. 20 min.						X	X				1955 colc
NOT WITHOUT HOPE - Presents complete diagnosis in young girl who develops epilepsy. Excellent historical and social perspective, creating awareness of problems and obstacles, role of the neurologist, etc. 23 min.	X	X		X	X	X	X	X			19[illegible] colc
NURSES TALK ABOUT EPILEPSY - Covers role of the nurse with attention to modern drug therapy. 13 min.								X			1975 colc
ONLY A PART OF LIFE - Shows that understanding plus an active normal life make epilepsy "only a part" on one's life. A positive vignette narrated by Arlene Francis. 5 min.	X	X			X	X					1967 B&W
ON THE GO - Case histories of teenagers and adults with epilepsy. Jack Linkletter as moderator inquires about the person's epilepsy and how it has affected his lifestyle. 25 min.	X			X		X					1962 B&W
SEIZURE - Film produced in response to the large numbers of soldiers who developed epilepsy subsequent to injuries in World War II. Handles the medical and social aspects of epilepsy realistically and positively; discusses problems of mid-career onset, disclosure to family and friends, job placement, medication. 30 min.						X			X		194[illegible] B&W

FILM ORDER FORM

Name _____ Film Wanted _____

Organization _____ Alternate Film _____

Address _____ Date Wanted _____

_____ Alternate Date _____

_____ (ZIP)

Phone _____ Type of Audience _____

Return to: Epilepsy Society of Massachusetts
3 Arlington St., Boston, MA 02116 617/267-4341

Please allow several weeks advance notice. Films are loaned free of charge but must be returned in good condition. You may wish to request a speaker from the Epilepsy Society.

OTHER TEACHING AIDS on EPILEPSY

DESCRIPTION	Type of Audience: General awareness	Teachers	Children	Teenagers	Parents	People with Epilepsy	Health Professionals (Gen'l)	Nurses	Emergency Medical Personnel	Employment Profs.	
EPILEPSY - A complete 2-tape cassette library on understanding and living with epilepsy, designed to help the family of the child with this disorder. Discusses (in enacted exchanges) tensions between parents, sorting out feelings and attitudes, effects on siblings, reactions of friends and neighbors, the school, being too protective/ too demanding, dating and other social involvements, planning for the future, sources of help, and other common concerns.*				X	X	X	X				1976
ON THE WAY TO WORK - A complete 2-tape cassette library on the vocational implications of epilepsy. Similar in scope to "Epilepsy" (described above) but designed for the employment counselor or rehabilitation specialist.						X				X	1976
SEIZURE DISORDERS: DIAGNOSIS AND CLINICAL MANAGEMENT - Multi-media medical education kit designed to upgrade the level of knowledge of primary care physicians in the management of epilepsy. Kit includes two audio cassettes integrated with slides, and two monographs and self-assessment materials. Primary care physicians may obtain 12 credits in category 1 of the Physician's Recognition Award of AMA. Kit is available at no charge to neurologists, directors of medical education programs, and other interested parties. Developed by Parke, Davis and Co.						X physicians					1976

The above teaching aids are available on a loan basis from the Epilepsy Society of Massachusetts; phone 617-267-4341 to make arrangements.

* Also available on single-day loan from the Mass. Dept. of Public Health Epilepsy Program (617-357-5002, x. 60).

ATTACHMENT N

Written Informational Materials Available
through the Epilepsy Society of Massachusetts, Inc.

Respond to: Workers with Epilepsy (for job-seekers--an aid to explaining epilepsy to employers)
Facts and Figures on the Epilepsies
The Role of the Nurse in the Treatment of Epilepsy
"Oral Tissue Reactions from Dilantin Medication..." (reprinted from the Journal of Periodontology)
Vocational Rehabilitation (introduction to Massachusetts Rehabilitation Commission)
The Second Injury Law--What Does It Mean? (a brief Q&A introduction)
A Patient's Guide to the E.E.G.
The Teacher's Role in Epilepsy
Research into the Epilepsies
Books on the Epilepsies
Pharmacopoeia of the Epilepsies
Epilepsy: Hope through Research (HEW)
Announcing Off-Peak Half-Fares for People with Special Needs (MBTA)
This Could Save Your Life (Medic Alert Foundation)
Can Epilepsy Be Prevented?
Teacher Tips on the Epilepsies
Benjamin (a comic book for elementary school children)
Medical and Social Management of the Epilepsies
Epilepsy and Insurance
The Employer's Role
There is Something Special about You (not specific to epilepsy, helps explain sibling with special needs to other siblings)
Handbook for Parents (excellent summary; Ayerst Laboratories)
Handbook for Patients " " " "
Pharmacy Service of the National Epilepsy League
Programs and Services for Workers (introduction to the Division of Employment Security, state employment agency)
Telling the Child with Epilepsy
Membership Information and Life Insurance Plan of Epilepsy Foundation of America

Other materials are available in limited quantity or can be perused. See also Attachments L and M. Materials in reasonable quantity are distributed as a public service. Contact the Epilepsy Society of Massachusetts, 3 Arlington Street, Boston, MA 02116; 617-267-4341.